Reconceptualising Endometriosis: Multiple Enactments and the A-Diagnostic Category

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ABSTRACT

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Endometriosis, a chronic disease that affects about 1.5 million women in the UK and 176 million women worldwide, is defined as the placement of endometrial-related tissue outside the uterus. It is characterized by painful menstrual periods, chronic pelvic pain, infertility, and pain during sexual intercourse. It has an average time to diagnosis of 7-10 years.

This thesis is based on an ethnographic study conducted primarily in the United Kingdom, which shed light on how health professionals and patients negotiate endometriosis. Utilizing Annemarie Mol's (2002) concept of disease ontology, this thesis explores the interplay between the multiplicities of endometriosis and the a-diagnostic category, a novel concept that I develop, with hopes of contextualising the struggle to access care for this condition. There are several reasons for a patient's movement into the a-diagnostic category. Historical understandings of menstruation and of the uterus limit what is presently considered endometriosis. Stigmatized notions of endometriosis and a 'lay-professional epidemiology' of the disease used by gynaecologists impede access to diagnosis. Interference with obtaining the endometriosis label can also be seen in the endometriosis movement, despite its advocating for women's gaining one unifying label. Teenagers, women of lower socio-economic status and of colour, and non-heteronormative/non-cis patients struggle to attain the endometriosis label. Enactments of endometriosis in the gynaecology clinic, as well as outside of it, are multiple and often clash over inclusion in or escape from the a-diagnostic category.

This thesis contributes to understandings of an underexplored, gendered, embodied experience of the disease, the effects of the extended delay to diagnosis, and the tensions around the endometriosis diagnosis. It is a context that is crucial for understanding the disease, its symbolic meanings, and for formulation of improved care of those suffering from endometriosis.

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LIST OF ABBREVIATIONS

ESHRE	European Society of Human Reproduction and Embryology
Endo	Endometriosis
F	Fieldnote
GP	General Practitioner
I	Informal Interview
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
O	Online Post
Q	Questionnaire
SSI	Semi-Structured Interview

STATEMENT OF COPYRIGHT

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À mes parents, Ezra et Brigitte Griffith et à mon frère Pierre Griffith:

Sans vous, je n'aurais jamais pu aller si loin.

Je vous aime de tout mon cœur.

DEDICATION

These words are dedicated to the 1 in 10

May your voices be heard, the battle cry sung and the war begun.
I sincerely hope this work contributes to awareness of endometriosis and to better health care and access for those who are seeking treatment for the disease.

Her Voice
Poem by Anna Chaplin *

She's missing pieces that were once her dreams, her hope now quiet, her pain only hers.
She cries for her freedom, now abandoned, now surrendered.
'Oh body', she quivers, 'please heal. The silence, the isolation, it's deafening'.
She deserves a voice.
This fight is for the strong and she knows it. It cannot defeat her.
There is a flickering light within, a fire that pain can never touch.
Her struggle kindles a movement for all those quiet dreams.
She finds her voice, the voice of us all.
These words are dedicated to the 1 in 10 women, like me, living with Endometriosis worldwide.

*https://www.facebook.com/EndometriosisAwarenessThroughArt/photos/a.436207796435518.98208.436188259770805/859531677436459/?type=1&theater accessed March 5, 2015

INTRODUCTION

I. General Comments

This is a story of pain, grief, loss, and struggle but also of hope and work towards positive change. In this thesis, I discuss endometriosis, a word and a concept that, as we will see, has many varied meanings for the different agents involved in its world. Using Annemarie Mol's *The Body Multiple* (2002) as a framework, this thesis argues that the many multiplicities of endometriosis not only complicate the meaning(s) of endometriosis but also ultimately serve to limit both who (and therefore which 'women') can be considered to have endometriosis and how endometriosis is defined. Based on an ethnographic study conducted primarily in the North-East of England, this thesis focuses on the multiple ways in which endometriosis is enacted and how these multiplicities ultimately impact access to care and advocacy.

My work draws on fieldwork conducted from June 2013 to August 2014. The study took place in several settings: a National Health Service (NHS) gynaecology clinic, a medical conference on endometriosis, the internet, various endometriosis support group meetings, and awareness campaign events. To my knowledge, this work represents the first ethnographic study on endometriosis that involves both women with endometriosis and associated medical professionals. Its multiple methods include a specific focus on visual representations of endometriosis posted on online media, a relatively new method in the field of endometriosis study.

Endometriosis is a chronic disease that affects approximately 10% of women worldwide (Tulandi and Redwine 2004), or 176 million women globally with 1.5 million women affected in the UK (Endometriosis UK 2018). The disease is characterized by the presence of endometrial-related tissue outside the uterine cavity. These cells, biologically similar to the tissue-lining of the womb, are found outside that organ and are called ectopic endometrial implants. When menstruation occurs, the ectopic endometrial implants bleed, thereby causing chronic pain, dyspareunia (pain during sexual intercourse), adhesions (scar tissue), and infertility (Tulandi and Redwine 2004, Redwine 2004, Fritz 2005). The cause of endometriosis remains unknown.

There are frequently extensive delays in diagnosis, with an average time to diagnosis of 7-10 years (Mounsey et al 2006). Denny and Mann (2008) talk of women with endometriosis being originally misdiagnosed as having Irritable Bowel Syndrome, depression, or of being told that their symptoms were normal. Because of its lack of cure and its chronicity, the endometriosis illness experience extends well beyond physical symptoms and has a significant impact on the quality of life of patients with the condition (Griffith 2009). This is further elucidated by 'The Letter from Survivors', which is found on many endometriosis patient websites and used for patient advocacy. The letter focuses on the validation of symptoms by doctors, partners, friends and co-workers and describes the endometriosis illness experience as one involving struggles with pain, infertility, and taking on the 'sick role' (Parsons 1951) in an 'unseen' disability (Unknown 1997). These patients view the doctor-patient relationship as overwhelmingly negative (Cox et al 2003a, Cox et al 2003b, Whitney 1998, Jones et al 2004, Griffith 2009).

Previous qualitative literature on endometriosis has focused on narratives of women with endometriosis and themes such as their disillusionment with medical professionals (Denny and Mann 2008, Cox et al 2003a, Cox et al 2003b, Whitney 1998, Jones et al 2004, Griffith 2009). Other work elucidates reasons for the notorious length to diagnosis of 7 to 10 years across the world that women with endometriosis experience. This time may in part be due to notions of menstrual stigma, for example (Seear 2014, Manderson et al 2008, and Markovic et al 2008). These studies do not generally compare the narratives of patients with endometriosis to accounts of doctors treating these patients and hence do not shed much light on the relationship between the two groups. The intention of this research is to address this omission.

In examining both doctors' and patients' enactments of endometriosis, I discuss why women with endometriosis struggle to receive the endometriosis label and have such seemingly negative experiences with their doctors. Addressing these matters through the lens of multiplicities allows for a move away from the simple binary notion of patient's narratives and doctor's narratives, and avoids the trap of considering these two

narratives as directly oppositional. Contemplating the multiple enactments of endometriosis favours a more nuanced discussion of how doctors and patient interactively negotiate this complex disease.

II. Terminology

A. 'Endometriosis Patient' versus 'Endometriosis Sufferer'

I debated at length which term would best describe my endometriosis patient research participants. I wondered, whether to use the term 'endometriosis patient', or 'endometriosis sufferer'.

The term 'patient' remains problematic for several reasons. First, I did not meet all of my research participants in the context of a medical clinic. Second, the term 'patient' does not describe how the illness affects a woman in non-clinical situations and in her other social roles. Patienthood suggests limitation by the boundaries of the medical encounter. As Conrad suggested:

> People who are sick only spend a fraction of their time in a patient role. While being a patient may be an important aspect of being ill, it is by no means the only one or necessarily the most important (Conrad 1990: 1260).

He pointed out that 'to the extent possible we must go beyond medical settings and focus on how people manage their illness (and lives) at home and at work' (Conrad 1990: 1260). In this thesis, I have described how women with endometriosis' understandings of their condition are connected to the clinic visit. I worried that using the term 'patient' somehow oversimplified women's experience by implying they only exist within the world of biomedicine and the medical setting. I have however, continued to use the term patient in the instance where women were seen and spoken to solely in the clinic and preserved such wording if used by medical professionals.

I also considered using the term 'endometriosis sufferer', which many of the women used to describe themselves. However, not all used this term. I felt it was not appropriate to apply it to all of my research participants. Even those who did use the

term ‘endometriosis sufferer’ rarely used the term ‘suffering’ in discussing their experiences with endometriosis. According to Jacqueline Atkinson, ‘suffering and being a victim are inextricably linked’ (Atkinson 1993: 118). She suggested that ‘suffering’ is an intrinsically passive concept. Therefore, it may be that as a ‘sufferer’ one does not fight. As many of the women in this study did very much see themselves as fighters against endometriosis, the term ‘sufferer’ seemed less appropriate.

In addition, using this term implies that the person is in a continual state of ‘suffering’.

> None of this is to suggest that illness does not bring suffering and that the ill do not suffer, but to concentrate on that, to label the whole experience of suffering, redefines the person’s life as much as the label patient (Atkinson 1993: 119).

The term suffering has also been linked to broader notions such as abjection (Kristeva 1982) that looks at the suffering linked to the collapse of human dignity into complete helplessness and self-eradication due to the force of another (Kearns 2002). Examples in the literature have included suffering linked to Nazi internment camps, or more recently the suffering experienced by those placed outside the government system of a nation-state such as refugees (Agamben 1998, Redclift 2013, Zembylas 2010). Within medical anthropology, the concept of ‘social suffering’ has been used to link suffering more broadly to notions of how social forces through political, economic, or social power inflict suffering on the human experience (Kleinman et al 1997). Women with endometriosis are unlikely to consider such concepts when using the term ‘sufferer’ in their own lives.

Finally, I rejected ‘sufferer’ because the women in this study all maintained hope in some fashion or another when discussing endometriosis. The term suffering partly overlooked the importance of the fight and of the hope they seemed so keen on passing on to others. By moving away from the ‘suffering subject’, as Robbins (2013) suggests, to an ‘anthropology of the good’ in which subjects are ‘pitched forward to … a better world’ (Robbins 2013: 459), the focus can be on how my subjects are looking forward to an improvement in care. I wish this to be an ethnography of hope, not one of ‘suffering’.

The best term therefore seemed to be 'woman with endometriosis'; however, even this term remains problematic, as not all the women in the study had a biomedical diagnosis of endometriosis. While most research participants did have an established diagnosis of endometriosis, some women visiting the clinic had not yet had a laparoscopy to confirm the endometriosis diagnosis. These women would therefore technically fall under the label of chronic pelvic pain if that were their presenting complaint.

In addition, one woman maintained that after her hysterectomy, as she had no symptoms, she no longer had endometriosis. For her, it was a past phenomenon. Therefore, she no longer considered herself to be a 'woman with endometriosis'. I also acknowledge that not all those who suffer from endometriosis consider themselves to be women. Nevertheless, in light of these considerations, I have chosen to use the term 'women with endometriosis' for the purposes of this thesis. This term most clearly suggests respectfully that the women have or, in one case, has had the disease but were not defined wholly by the illness.

B. 'Woman' and 'Womanhood'

I have used the term 'woman' and 'womanhood' in this ethnography, but not without much thought and care. With recent calls by non-cisgender endometriosis 'sufferers' to move away from the notion of endometriosis as a disease of women, it is certainly an important issue to address. The majority of the participants with endometriosis in my study considered themselves women. The only exception to this was in my data from online sources. Thus, endometriosis remains a disease seen as inescapably linked to womanhood, both historically and in the present day.

Of course, the issue at hand is multi-factorial. There are scattered case-reports in the medical literature of endometriosis found in XY genomic men (Rei et al 2018). But, aside from this, endometriosis is a disease found in females (XX). Thus, I have used a general term of 'woman/women' with endometriosis. Of course, those who do not identify as women have not been labeled as such. Here, I have taken care to address

them as they wish to be addressed. This, however, does not become an issue until the last chapter (Chapter 9) where I discuss this very matter in more detail.

C. 'Endometriosis' versus 'Endo'

There remains a clear distinction between the medical professionals' use of the term 'endometriosis' and the women's common use of the abbreviation 'endo'. This difference may have resulted from the view that endometriosis is a fairly long and complicated word to both say and spell. Some members of the endometriosis awareness movement felt it was not good to use the term 'endo', as it was also a nickname for marijuana, and therefore inappropriate terminology. Some women also explained that the term 'endo' served as a diminutive and maintained endometriosis as a politically unimportant condition. I will therefore use the term 'endometriosis', but I have kept the terms used by my research participants. If any woman has used the term 'endo', I have left her words and the use of that term intact.

D. 'Endometriosis' or 'Endometrioses'

In this thesis, I will talk much about the multiplicities of endometriosis, which some would argue means I should use the term endometrioses and not endometriosis. This is a central issue in my thesis, one that is explained in greater detail in Chapter 1. However, briefly, I underline here that while the importance of the endometriosis multiplicities deserves emphasis, I want also to acknowledge women's views on the importance of one endometriosis, as one label, a diagnosis that they struggled to obtain. I cannot argue the case of multiple endometrioses when women with endometriosis/endometrioses do not. They are quite clear that they all suffer from a singular entity, a label they spend years seeking. They may experience it differently, but they are fighting for the same thing: first and foremost, for the condition to be acknowledged, for each patient to receive the diagnosis. This requires the recognition of one label, which I risk undermining if I begin to use the term 'endometrioses'.

To focus on the question 'which endometriosis is it' of the multiple endometrioses misses the forest for the trees. The main question to ask is how they become endometrioses at all. Women with endometriosis struggle for the label 'endometriosis' not 'endometrioses'. This is for a very specific reason. In contrast to atherosclerosis(es) (Mol 2002), endometriosis remains something women struggle to 'get'. They want the term, they seek a name for their physical struggle, the one they draw, they paint, they express in any way they can: 'endometriosis'. Without it, women with endometriosis remain 'crazy', 'weak', 'normal' or just suffering from period pain.

I suggest that the multiplicities of endometriosis serve as a useful model of the disease and of its many biomedical and social trajectories. However, there are still several groups that seek the unitary label of endometriosis because it reduces confusion and enhances their objectives. Perhaps the most partisan group in favour of the singular 'endometriosis' is the pool of individuals who suffer from this disease that can be so severe, unrelenting, and a significant lifetime burden. Throughout the thesis, I will use the term endometriosis unless I specifically want to emphasize its multiplicity when I will use the term 'endometrioses'.

E. The A-diagnostic Category

I explore the reasons for the notoriously long time to diagnosis of endometriosis across the world (an average of 7-10 years) and the negative interactions between doctors and women with this condition. By considering the multiple enactments of endometriosis, I examine the struggle to gain the endometriosis label. I argue that the complexity of such multiplicities of endometriosis is accompanied by a simultaneous limiting of understandings and definitions of 'endometriosis', such that the term generally remains limited to a disease of 'white, cis, heterosexual, and professional' women. At the same time, even this group of women struggle to receive the diagnosis of endometriosis despite seeking care from medical professionals.

The paradoxical notion of multiplicities of a disease being linked together by one term requires of course the existence of that label and the ability to easily access such a

diagnosis. While Mol (2002) describes such a scenario in atherosclerosis, she focuses on enactments of atherosclerosis such that there are no queries around whether, for example, atherosclerosis exists or whether certain groups of patients actually have atherosclerosis at all. This is in sharp contrast to endometriosis, in which the medical community questions at times its very existence (Seear 2014), and where it has been documented that women with endometriosis consistently feel they are told their symptoms are 'all in their head' (Griffith 2009, Denny and Mann 2008, Cox et al 2003a). Thus, from the notion of disease multiplicities, I develop a new concept: the a-diagnostic category, an idea I hope will be applicable to other illnesses as well.

This a-diagnostic category is a classification where patients have been given an explanation for their symptoms but such explanations remain non-medicalised such that subsequent treatment is not given. An explanation within the a-diagnostic category means the patient cannot access a 'diagnosis' or be considered for other possible 'differential diagnoses'. In endometriosis, the a-diagnostic category applies to patients who describe symptoms that are acknowledged as abnormal but considered by physicians as either physically normal ('normal period pain'), or described in emotional terms such as 'depression'. In this instance, endometriosis remains outside the potential differential diagnoses and the symptoms remain untreated; this leaves the woman without access to a diagnosis and without access to medical care for her symptoms. I discuss the interplay between the multiplicities around endometriosis and the a-diagnostic category. Patients within the category of diagnosed endometriosis may move into the a-diagnostic category. This occurs in the case, for example, of those who despite the diagnosis are not responding to the usual treatment protocol. Patients may also move out the a-diagnostic category but only with much difficulty. By gaining the label of endometriosis, they find it much easier to access needed medical care.

It is important to address the terms movement into the a-diagnostic category. Women with endometriosis transition into the a-diagnostic category primarily because of actions by medical professionals (often GPs and gynaecologists). However, this positioning in the a-diagnostic is not something that medical professionals or others may acknowledge

or even recognize. It is not a medical category either officially or unofficially. Instead, it is an ethnographic category that has emerged directly from ethnographic data and a classification I have labelled or named so as to move forward the discussion of enactments of endometriosis. Thus, I do not intend that movement into the a-diagnostic category be seen as a formalized decision on the part of medical professionals.

IV. Overview of the Thesis

In the first chapter of the thesis, I begin with a theoretical framework. In Chapter 2, I discuss the methods used in this study and matters relating to research ethics. I also present the different spaces in which I conducted my research. In Chapter 3, I articulate a brief history of menstruation and its relationship to attribution of the endometriosis label, thus limiting what is considered within the box of multiplicities labelled endometriosis. Such historical notions of menstruation as 'normally painful' are relevant to understanding how women with endometriosis find themselves in the a-diagnostic category.

In Chapter 4, I discuss the a-diagnostic category in more detail. I point out the effect of staying in such a category and being unable to receive a diagnosis. I describe the trajectories through which women may escape the a-diagnostic category and obtain the endometriosis label, and the after-effects of finally receiving a diagnosis.

In Chapter 5, I examine how the multiplicities of endometriosis play out in the gynaecology clinic. I argue that while gynaecologists distribute the multiplicities in ways that allow for pragmatics to dominate, they also limit who can be considered to have endometriosis. They use what I call 'lay-professional' epidemiology, to circumscribe the endometriosis category and render the endometriosis label all the more elusive.

Starting from notions taken from Foucault concerning disciplinary power, in Chapter 6 I suggest that the gynaecology clinic is a space where doctors and nurses both act as links to the practical exercise of what I call 'control strategies' even while they may

simultaneously feel powerless and limited by disciplinary power. Thus, they resort to strategies to regain control as techniques to resist the pressure of systemic dominance. These control strategies are used by women with endometriosis mainly as a way to gain the endometriosis label and therefore a way out of the a-diagnostic category; while gynaecologists use control strategies to subvert a system pressuring them to diagnose and cure every patient. The latter often leads to patients being pushed out of the medical system and back into the a-diagnostic category.

In Chapter 7, I consider enactments that occur both inside and outside the biomedical clinic. I return to notions highlighted in Chapter 3 and examine particularly stigma of menstruation, of sex, and of childlessness. They limit who is given the endometriosis label and help determine entrance into the a-diagnostic category. Chapter 8 examines enactments of disease (in this case endometriosis) that take place outside of the clinic and outside of biomedicine. Such enactments, particularly where notions of endometriosis are linked to mental health matters sharply distinguish medical notions of endometriosis from psychological issues, such that psychological notions remain linked here to the a-diagnostic category and often predominate and become reasons women find themselves back in the a-diagnostic category.

In Chapter 9, I turn to the endometriosis movement, a movement linked to one label whose definition appears partly to be fixed and therefore singular. Its association with one name, one diagnosis, and therefore a form of biosociality (Rabinow 1996), does not mean that there are no multiplicities present. Instead, this chapter discusses a visible struggle to reduce multiplicities into a manageable single diagnostic entity. Thus, people involved in the movement emphasize which of the multiplicities of endometriosis are to be prioritised, arguably acting like gynaecologists (in Chapter 5) limiting who is considered to have endometriosis and which endometriosis experience should be prioritized.

The conclusion reviews the major findings of this thesis, discusses potential solutions or at least beginnings of ways forward, and suggests future directions for research. It also

provides ways in which the insights provided may contribute to improving care of patients suffering from endometriosis.

CHAPTER 1

Theorising the Framework

I. Introduction

In this chapter, I formulate the theoretical framework that undergirds my work. I begin with a discussion of the biomedicine of endometriosis that serves as a general introduction to this chronic illness that afflicts so many women throughout the world. I then move on to understandings of endometriosis outside of biomedicine. I make use of Annemarie Mol's (2002) concept of the multiplicity of disease and Michel Foucault's (2004) concept of biopower to articulate a narrative about this disease and the ways in which it affects the daily lives of those who suffer with it. I also introduce the notion of the a-diagnostic category, which should shed additional light on the understanding of endometriosis.

II. Biomedical Descriptions of Endometriosis

It is a bit ironic to begin a thesis on the multiple enactments of endometriosis with a definition of the disease. But, it is important in a discussion of endometriosis to define biomedical models of the disease, and to provide a clear explanation of its pathophysiology, clinical presentation, and current treatment. Endometriosis is a disease primarily affecting women, with only rare cases involving men. It is characterized by the presence of endometrial-related tissue outside of the uterine cavity. The endometrium is the most superficial lining of the uterus that sheds every month to produce what we commonly call menstruation. In women with endometriosis, areas of endometrial-like tissue are found as implants outside of the usual uterine location. These extra-uterine spaces are called 'ectopic' locations. Endometriosis is an important cause of pelvic pain and infertility, and approximately one in 10 women worldwide are thought to suffer from it (Redwine 2004, Tulandi and Redwine 2004, Fritz 2005).

The earliest formal studies on endometriosis were published by Sampson in 1921, and he was the first to employ the term "endometriosis" in a 1925 publication (Sampson 1927). However, previous descriptions of endometriosis used other terminology to refer to this clinical entity. Sampson, who published 18 articles as a sole author, remains a key source on terminology and theories of endometriosis. His ideas still

permeate clinical discourse on endometriosis (Clement 2001). The cause of endometriosis remains unknown. The pathophysiology of endometriosis and associated pain symptoms is not well understood; nor is the link between endometriosis and infertility.

While the major symptoms of endometriosis are pelvic (lower abdominal) pain and infertility, dysmenorrhoea (pain during menstrual periods), intermenstrual pain (pain between menstrual periods), and dyspareunia (pain during sexual intercourse) are quite common. The pain is often dull, aching, diffuse, and deep in the lower abdomen, though it may radiate to the lower back and thighs. Patients may also complain of nausea, episodic diarrhoea and rectal pressure (Fritz 2005). In addition, endometriosis can involve any organ system including brain, lungs, bladder, intestines, umbilicus, and sciatic nerve. Extrapelvic endometriosis (endometriosis outside of the pelvis) is associated with a wide range of frequently cyclical symptoms associated with the organ involved (Fritz 2005).

The only definitive way to diagnose endometriosis is through surgical visualization, excision and confirmation by microscopic analysis. Laparoscopy (keyhole surgery) is used most frequently in both the United Kingdom and the United States. In this procedure, an instrument is inserted through the abdominal wall to view organs in the abdomen and to perform surgical procedures. Other methods such as Magnetic Resonance Imaging (MRI), X-Ray and ultrasound (scan) do not have strong diagnostic accuracy for endometriosis. In addition, pelvic exams are also unreliable for measuring the extent of the disease progression (Practice Committee of ASRM 2006a, Practice Committee of ASRM 2006b). Because the gold standard for diagnosis of endometriosis is of a surgical nature, a good history and physical examination are essential in leading clinicians towards sharpening their suspicion of the correct diagnosis. Physical examination may reveal tender nodules located in the posterior vaginal fornix (superior, arched area of the vagina), uterine motion tenderness, as well as tender adnexal masses (located close to the uterus). On examination, endometriosis patients may also present without any such signs.

Because the differential diagnosis of chronic pelvic pain is quite extensive, it can be difficult to reach a diagnosis of endometriosis. To differentiate between endometriosis and adenomyosis, pelvic inflammatory disease, congenital anomalies of the reproductive tract, disorders in the gastrointestinal, neurological, urinary or musculoskeletal systems, patients ought to be evaluated thoroughly before initial treatment and should be re-assessed in cases of treatment failure (Practice Committee of ASRM 2006a, Practice Committee of ASRM 2006b).

Treatment of endometriosis can be either through medical or surgical means. Medical treatment for endometriosis involves hormonal therapy to alter the menstrual cycle during the reproductive years (Fritz 2005). Pain can also be treated with different medications including non-steroidal anti-inflammatories such as mefenamic acid or ibuprofen (Valle 2002, Wieser et al 2007) or treatments for neuropathic pain such as amitryptyline or gabapentin.

Infertility due to endometriosis can be treated with ovarian stimulation (by for example the drug clomid) with or without Intrauterine Insemination after laparoscopy (keyhole surgery) in patients in the early stages of the disease (Hompes and Mijatovic 2007). In cases of failure with this approach or in severe disease affecting the ovaries or the fallopian tubes, the use of In Vitro Fertilization (IVF) has been recommended (Hompes and Mijatovic 2007).

Generally, the surgical treatment of endometriosis falls into two categories: that aimed at eliminating endometriotic implants, and that aimed at decreasing pain specifically (Redwine 2004). The first class involves laparoscopy, considered first line, or hysterectomy, generally thought to be a far more serious intervention due to the effect on fertility. The second type of surgery includes presacral neurectomy (removal of the group of nerves that transmit pain signals from the uterus to the brain) and laparoscopic uterosacral nerve ablation (LUNA) (Redwine 2004).

III. Endometriosis Outside of Biomedicine

Endometriosis is, of course, much more than its biomedicine. Endometriosis has long been considered a disease of women, and often the 'career woman's' disease (Capek 2000). It is a disease that through research has been limited to white, heterosexual cis-women, with academic literature largely excluding women of colour with endometriosis (Kyama et al 2007 and Denny et al 2011) and non-cis women with endometriosis about whom, to my knowledge, no articles have been published. This is despite active endometriosis support groups across Africa (Kenya and Tanzania) and the Caribbean (Trinidad, Jamaica, Barbados).

It is a disease that causes pain, which women describe as 'intractable' and controlling (Huntingon and Gimour 2005). It is a malady that causes pain during sexual intercourse, and that provokes severe, chronic pain (Jones et al 2004, Huntington and Gilmour 2005, Denny 2007, Gilmour et al 2008). It is also a disorder which affects women's efforts to fulfill specific roles in society as mother, sexual partner, friend, and co-worker (Jones et al 2004, Gilmour et al 2008, Griffith 2009, Hudson et al 2016). It also causes life disruption (Jones et al 2004, Wang 2004, Gilmour et al 2008, Griffith 2009, Hudson et al 2016, Manderson et al 2008), like other chronic illnesses, especially those linked to chronic pain (Bury 1982 Charmaz 1983, Harris et al 2003). It is an illness that 'drains our confidence, leading us to hate our bodies. It boldly steals from us our dreams, career, relationships, friends, and the right to a decent life' explains Wang (2004: 1800) in her personal illness narrative of endometriosis published in the Lancet.

Endometriosis forces women into much extra work, what Seear (2009c) describes as the 'third shift', just trying to find forms of treatment outside of biomedicine. Others found that women felt it necessary to search for additional information about the condition, be it biomedical or other information in order to understand further and regain power over their lives (Ballweg 1997, Denny 2004, Whelan 2007, Griffith 2009). This pattern is similarly echoed in other chronic illnesses such as diabetes (Thorne et al 2000, Loader et al 2002).

Endometriosis carries stigma of its own that limits women's ability to talk about it (Griffith 2017). Women with endometriosis consider it a private affair and are often uncomfortable speaking with male employers about the disease because of its status as a reproductive disease associated with menstruation (Gilmour et al 2008). This has been echoed by authors who focused on the social etiquette surrounding menstruation (Laws 1990, Seear 2009b).

It is a disease about which not much is known. The pathophysiology remains questioned, and ultimately, its status as a diagnostic category remains in flux (Seear 2014, Capek 2000, Seear 2009a). Its position as a contested disease category means that women look for validation from both the medical profession and from social support networks because of their feelings of not being believed, especially by medical professionals but also by lay people (Whitney 1998, Cox et al 2003a, Cox et al 2003b, Denny 2004, Jones et al 2004, Denny 2008, Griffith 2009). Thus, women seek validation of their experiences with the disease and wish to be believed by those hearing their reports (Whitney 1998, Griffith 2009, Denny 2004). They want their support system to be knowledgeable about the disease and able to understand the symptoms of endometriosis so that they can explain to others their knowledge of endometriosis (Whitney 1998).

As is the case with many other chronic illnesses (Rabinow 1996), women with endometriosis often band together through forms of biosociality (Neal and McKenzie 2011, Whelan 2007, Griffith 2009, Emad 2006) particularly online, where they form online endometriosis support groups. Whelan (2007), for example, concluded that the illness experience created a basis for solidarity among members of the endometriosis community, allowing them to define themselves as insiders in contrast to the outsiders who are those without the endometriosis illness experience. The enactment of endometriosis was considered a type of knowledge that only the members could know, making all outsiders, including the medical community, at best 'pseudo-experts' on endometriosis. Whelan specifically addressed the use of the online support group as a

method of gaining both medical and what she called 'experiential' knowledge in response to clinician's 'unwillingness to share information with patients' (Whelan 2007: 978).

Endometriosis is also a disease where disillusionment with the medical profession and an apparent lack of trust in clinicians are common (Whitney 1998, Cox et al 2003a, Jones et al 2004, Griffith 2009). Women speak of clinicians' negative attitudes and the resultant trauma and depression experienced by the women after negative clinical encounters (Cox et al 2003a). This has led to endometriosis patients feeling pressured to become more assertive in communicating with their clinicians (Cox et al 2003a, Denny 2008). The women also sometimes seek other forms of treatment in a effort to avoid the biomedical system (Griffith 2009, Seear 2009a, Cox et al 2003b).

IV. Multiplicities of Disease

Even with my brief descriptions of endometriosis to this point, one may see that endometriosis is hard to define as only one entity. At surface level, its multiplicities are perceptible. Patients make their opening statements to professionals. Gynaecologists make their entrance to excise tissue from the abdomen. Pathologists examine that tissue under the microscope. Family members and others discuss their own experiences with women who have the disease. Still others, in their unique encounters, may bear witness to their interactions with endometriosis. Particularly prominent is the potential for different understandings of the disease by two main groups of participants in this work (doctors and patients). I set out to examine doctors' and patients' narratives of endometriosis, but without wishing to place these two groups at odds by exacerbating potential disagreements. It is key to remember that both groups should have a single goal: improving the care of women with endometriosis. Speaking of multiplicities may allow for a more productive discussion of how to improve care in this complex area of medicine by clarifying the potential problems without blaming one or the other group.

Mol (2002) has suggested that medical anthropologists should abandon the artificial distinction between disease and illness for effectively the same reason. She argued that

speaking of illness narratives as opposed to biomedical disease only serves to place the illness narrative firmly outside of the realm of medicine, when ironically our goal as medical anthropologists is that such narratives be considered as part and parcel of medicine (Mol 2002). Similarly, addressing multiplicities and the multiple enactments of endometriosis may allow for a cohesive and less confrontational analysis. Mol's emphasis was on grasping what occurs in practice, especially in diagnosing and treating diseases. This requires cooperation of those involved in the enactments (Mol 2002).

Annemarie Mol has been a major influence on the theorising of chronic disease. She (Mol 2002) wrote an ethnography, and ultimately what she called a praxiography, on atherosclerosis in a hospital in the Netherlands. *The Body Multiple* looked at the way in which, as she put it, medicine enacts atherosclerosis. Mol presented multiple enactments of atherosclerosis, focussing primarily on differences between the clinic and the pathology laboratory. She showed that diseases and bodies can and should (in her view) be considered both multiple and singular at the same time, with her main argument being one of viewing not only diseases, but bodies as multiple and at the same time singular, and that 'reality is multiple' (Mol 2002: 6 top). This idea of many but one (the body multiple) is central to her text. For her, there are many atherosclerosis that are enacted in the hospital, but this multiplicity still must be integrated under one name or one diagnosis. So multiple atherosclerosis exist, while at the same time they are unified under the atherosclerosis diagnostic label.

Mol (2002) described different formulations of arterial blockages (atherosclerosis) that physicians could conceptualize. An arterial block could result in a cardiac complaint and the patient's referral to a cardiologist. In contrast, blockage of the artery in the nervous system could result in a stroke and the patient's consultation with a neurologist. On the other hand, a general practitioner might worry about the level of cholesterol in the patient's blood. Thus, these different practitioners are thinking about atherosclerosis and its effects on different body systems. They are all enacting atherosclerosis in particularized ways. In the case of endometriosis, it is the gynaecologist who seems to bear the burden of enacting conceptualizations of the illness. While the effects of

atherosclerosis can be found in a broad cross-section of patients (male, female, young, old) and in many organ systems, with endometriosis, the definitional manifestation (itself an enactment of endometriosis) is linked to the ectopic location of endometrial-like tissue outside of the uterus. So, whether the ectopic location is in the eye, the digestive tract, or elsewhere, all suspicion of endometriosis involves interrogation of uterine function and structure, which requires the involvement of the gynaecologist. But the unified appeal to a single specialty does not eliminate the problem of multiple notions of endometriosis. Gynaecologists make their own decisions about pragmatics, based on the implications regarding the patient's every-day functioning. But other specialists may still have to be involved in the care of the patient, depending on the significance of the disease impact on the organ involved. Variations in formulation of the meaning of the diagnosis come from location and effect of the ectopic cells on particular organs, intensity of the primary abdominal pain, bleeding, and state of the relationship with spouse and family.

Mol stated that in the clinic or the hospital, different physicians may enact the same disease in different ways. But other elements affect these enactments. Maleness or femaleness, she argued, interacts with the enactment of disease, causing new forms of enactments. I would add to this that gender, sexuality, socioeconomic status, and race may also influence enactments of endometriosis. Applied to endometriosis, this means that some women are excluded from the potential endometriosis label and find themselves in what I have called the a-diagnostic category. This enactment may have significant consequences.

V. The Search for a Unitary Diagnosis

The notion of multiplicities requires, of course, one label with which to unify the multiple enactments of disease. Endometriosis challenges the notion of diagnosis as fixed and uncontestable, thus suggesting that it may be better to consider the multiplicity of endometriosis and how multiple endometrioses lead to conflicting notions of what really is endometriosis and what should be called endometriosis.

Diagnosis has been discussed in the literature as both a category and a process (Blaxter 1978, Jutel 2009).

> A diagnosis is both the pre-existing set of categories agreed upon by the medical profession to designate a specific condition it considers pathological, and the process, or deliberate judgement, by which such a label is applied (Jutel 2009: 278).

Thinking about diagnosis usually leads to the classic idea of the ICD (International Classification of Diseases) which doctors use to classify and categorize diseases (Blaxter 1978). Here, each disease category serves to determine treatment options and how much doctors get paid for each patient and each intervention (in certain medical systems).

In contrast, when thinking about diagnosis as a process, it becomes the pathway by which patients obtain this classification. It is the means by which doctors reach a conclusion and ultimately give patients a label. For Jutel,

> [Diagnosis] organises illness: [by] identifying treatment option[s], predicting outcomes, and providing an explanatory framework. Diagnosis also serves an administrative purpose as it enables access to services and status, from insurance reimbursement to restricted-access medication, sick leave and support group membership and so on (Jutel 2009: 278).

However, these two ways of considering diagnosis assume a static view of these processes. Intrinsic to diagnosis as category or process is the idea that once the process has taken place and the category is ascribed, it cannot be withdrawn unless the patient recovers. The assumption is that once a patient is given a diagnosis of a chronic illness, the label cannot be questioned and is constant. However, this is not the case with endometriosis. Gynaecologists in this study assigned the endometriosis label and then revoked it.

Diagnosis can also be thought of as a tool that implements the social construction of illness, with 'diagnosis represent[ing] the time and location where medical professionals and other parties determine the existence and legitimacy of a condition' (Brown 1995: 38). While diagnosis can determine whether a condition is considered 'legitimate', it

also can be used as a tool for social control (Conrad 1992) by determining the boundaries between normal and abnormal and providing the labels which are then used in society. The social use of diagnosis can be for anything, from welfare and unemployment benefits (Brown 1995) to allowing patients to take on the sick role (Parsons 1951) and to creating new narratives around the illness (Bury 1982). Diagnostic categories are often the subject of controversies, as shown in recent examples with depression, attention deficit hyperactive disorder (ADHD) (Moncrieff and Timimi 2013), and chronic fatigue syndrome (Richman and Jason 2001). Ultimately these categories may or may not be accepted or applied (Brown 1995).

Carolyn Smith-Morris's edited volume (2016) challenged the notion of diagnosis as fixed and uncontestable. Smith-Morris suggested that it was often difficult to achieve diagnostic clarity, and that such clarity may not last. For her, diagnosis is 'a way of creating uniformity and order' (Smith-Morris 2016: 7), with its goal to 'create or identify order from chaos' (Smith-Morris 2016: 9), and yet at the same time diagnoses are continually 'modified to better capture those at risk' and new diagnoses appear as environments and organisms evolve. Thus, 'pressure towards uniformity and clarity, then, is met with constant resistance' (Smith-Morris 2016: 5) through diagnostic controversy, with 'certain diagnoses constantly grappl[ing] with fluid contexts, differences in appearance and presentation, and sincere disagreements at the highest scientific levels to the everyday encounters between patients and their healers' (Smith-Morris 2016: 9). Mol (2002) pointed out, however, that a fixed label may not tell us much about the practice of living with a body that has the disease. There is an inherent tension between the multiple stories we hear about a condition and the constant biomedical push to utilize unitary diagnostic labels.

A. Diagnosis and the Sick Role

In Western culture, the physician establishing a diagnosis helps to validate an individual's symptoms (Delea, Accessed 5 January 2010). This facilitates the legitimization of the illness experience and therefore the psychosocial impact of the

disease, amongst friends and family as well as the patient (Kleinman 1988). When doctors do not legitimize the disease, as in the case where they do not provide a diagnosis or where they find it difficult to explain symptoms by a disease process, then the patient struggles to have her illness experience legitimized (Delea, Accessed 5 January 2010). The many gaps in our medical knowledge of endometriosis as a disease process lead, therefore, to a mistrust of the illness narrative told by women with endometriosis. If a clinician is unclear as to what actually causes the pain symptoms of endometriosis, this doubt regarding the disease may translate to a doubt in the patient herself (Griffith 2009).

Once diagnosis has been achieved, it has been thought to allow patients to take on the sick role successfully (Parsons 1951). Endometriosis is no exception to this. A diagnosis of endometriosis may help women's complaints gain legitimacy with doctors. It may also allow for increased access to care and treatment, thereby limiting the effect of endometriosis on personal relationships and fertility (Denny 2004, Denny 2009, Cox et al 2003b, Manderson et al 2008, Santos et al 2012). The endometriosis label comes with responsibility, with a social obligation of self-care, something Seear (2009c, 2014) found in relation to women with endometriosis in Australia. The idea has also been widely discussed about various chronic illnesses (Parsons 1951, and Rose and Novas 2005).

At the same time, diagnosis allows for access to forms of biosociality, a term first coined by Rabinow (1996), and the associated concepts of biological citizenship (Rose and Novas 2005), and technoscientific illness identities (Sulik 2009, Sulik 2011a, Wehling 2011) which have been used to explain the collective identity of individuals with unifying biological features such as specific genetics or illnesses like neurofibromatosis. Endometriosis is another good example that has produced groups forming to share experiences and lobby on behalf of individuals with the condition. In endometriosis, biosociality leads to decreased isolation in women (Griffith 2009, Whelan 2007, Whitney 1998). In Chapter 9, I discuss the formation of the endometriosis movement and the sharing of tools that facilitate access to medical care.

B. History of Diagnosis

It is only since the mid-nineteenth century that modern notions of diagnosis have come about, characterized by specific diseases being thought of as separate from individuals. Diseases start to have a clinical course and an underlying cause with its associated pathophysiology. The practice of diagnosis now begins to consist of placing the patient within the clinical narrative (Rosenberg 2002, McGann and Hutson 2011). With this came a focus on clinical signs, and a move away from the patient narrative, as tools to diagnose disease. Thus, reliance on physicians' senses such as palpation, percussion, or observation of clinical signs became more important, as did the use of technology to diagnose disease entities. Diagnosis was no longer linked solely to a patient's experience of disease, and a patient's reported symptoms were treated with suspicion. (Reiser 1978, Rosenberg 2002, McGann and Hutson 2011)

This effectively created a split between enactments of disease outside of the clinic (where patients' experiences of the disease were prioritized) and enactments within the clinic (emphasizing biomedical notions of illness). 'As long as patients were willing to surrender their subjective experience to expert authority', such a system of diagnosis worked well, at least in theory (McGann and Hutson 2011: xvi). However, by the mid-twentieth century, numerous articles focussed on the clash of enactments of disease outside of biomedicine and biomedical notions of disease. Examples included patients with 'asymptomatic illness' who might refuse a diagnosis, patients who disregarded clinical advice, and patients who presented with symptoms that were not backed up with physical signs or laboratory tests and who therefore had no discernable 'organic' cause of disease (McGann and Hutson 2011). Modern diagnosis still must contend with this wall between patients' experiences of disease and doctors' 'technologically mediated pictures of disease' (McGann and Hutson 2011: xvi).

This has resulted in 'physicians often look[ing]… to psychiatry for a rich vocabulary to account for the discrepancy between disease and illness experience' (the patient experience of illness) with terms such as functional disorders, hypochondriasis and somatising disorder (McGann and Hutson 2011:xvii). Such medical explanations of

bothersome patient behaviour show a 'what philosopher Paul Ricoeur (1974) calls "hermeneutics of suspicion" where the patient's narrative is seen as distorted and the distortions attributed to an underlying mechanism' (McGann and Hutson 2011: xvii). These gaps between disease and illness or the gaps between varying enactments of disease mean that patients often feel invalidated and left with few options but to find a new doctor, go home, or follow the doctor's suggestion to seek psychiatric help (McGann and Hutson 2011).

VI. The A-Diagnostic Category

It was in listening to women with endometriosis that I discovered the salience of their search for a diagnosis to put order and meaning into their complaints about pelvic pain and heavy periods. Many women reported spending as many as twenty years looking for a label for their complaint. They were often told it's just a painful period, so stop complaining. Others talked of being referred to a consultation with a psychiatrist. The common experience of being dismissed by doctors meant not only that they struggled to access care, but also that they were not considered by doctors as having endometriosis. The pursuit of a diagnosis and the feeling of being truly believed became the prominent issue here. I found there was no good phrase for this concept of the label endometriosis being out of reach. So I present the a-diagnostic category, an ethnographic classification that symbolizes the lack of a diagnosis. I use the term 'a-diagnostic category', making use of the Latin root 'a-' or 'ab-' meaning 'without'. The a-diagnostic category means literally a category without a diagnosis.

The a-diagnostic category denotes being without a diagnosis. It also serves as an impediment to receiving a diagnosis. Positioning in the a-diagnostic category means that the diagnosis is difficult to achieve. The a-diagnostic category is a place where the symptoms the patient describes are acknowledged as abnormal either physically, or in emotional terms. The disease remains outside the list of potential differential diagnoses. The abnormality may be medical, but often is non-medicalised and represents an 'explanation' of the symptoms. Efforts to explain these patients' complaints do not lead

to a clear diagnosis. Endometriosis is excluded or ignored as a potential cause of the women's symptoms.

Is this a case of pre-disease? The notion of pre-disease has begun to permeate the practice of medicine. One common example is the case of pre-diabetes in internal medicine (Tabak et al 2012). The a-diagnostic category is not a form of pre-disease, as pre-disease generally represents the early onset of an established category and provides patients a label recognized by clinicians and associated with treatment protocols. In addition, the notion of pre-diabetes suggests that the condition may evolve to the next phase of the full-blown condition of diabetes.

I have considered whether positioning in the a-diagnostic category can be considered medically unexplained symptoms (MUS). However, medically unexplained symptoms – ironically represent a category (found in the international classification of diseases), within medicine to include those patients who have symptoms without an identified organic cause (Nettleton 2006). My suggested use of 'a-diagnostic category' conveys more fully a process that defines a complex enactment of non-diagnosis formulation that includes elaborate and sustained implications for the patient.

Women in the a-diagnostic category recognize a presence of disease that has not yet been acknowledged by medical professionals. However, patients themselves may recognize that their complaints prevent them from fulfilling certain expected roles in society. They then find themselves in a state of suffering, one they recognize as not normal but pathological (Canguilhem 1991). This determination that something is wrong and there is impaired functioning may of course come from the doctor or from the patient who recognizes her abnormal state (Mol 2002). The determination of what can be considered in need of treatment, does not depend then solely on the doctor, but also on the patient. Women in the a-diagnostic group see themselves as ill, even though the doctor is not in agreement.

The a-diagnostic category comes into sharp relief when the doctor does not recognize that something is wrong, but the patient still feels that there is. A conflict results. There is a difference of opinion between clinician and patient. Because the doctor is largely responsible for determining when something is considered pathological, particularly in the clinic or the hospital (Foucault 1963), and for providing a diagnostic label (Parsons 1951), patients struggle for acceptance of what they consider disease. Patients' negative feelings linked to delay in diagnosis may be related to a 'degree of embodied doubt and uncertainty' which has been noted in those 'who experience debilitating symptoms for which there is no explanation, label, diagnosis, prognosis or treatment' (Nettleton 2006: 1167). The differentiation between the 'normal' and the 'pathological' becomes key then to why patients find themselves in the a-diagnostic category and how they can escape it.

The a-diagnostic category is one which includes both other 'medical diagnoses' as well as entities that are not have not made their way into the clinical lexicon and have yet to be medicalised (such as 'normal periods'). Literature on medicalisation generally has discussed social control of medicine and the creation of new medical categories often in psychiatry (hyperactivity, child abuse, PTSD or alcoholism) (Conrad 2005). Medicalisation of women's bodies has been the subject of much discourse in relation to child birth or menopause, for example (Foucault 1978, Bell 1990, Martin 1987, Conrad 1992, Conrad 2005). Such discussions have generally been a critique of medicine, where the medicalisation of women's bodies has been seen to go too far (Martin 1987, Teman 2010).

The a-diagnostic category may be something that women experience more often than men. I suggest this, as women have longer time to diagnosis in various conditions, and are known to be less likely to be believed by their doctors than men presenting with the same set of complaints (Ballweg 1997), particularly when it comes to pain symptoms. Specifically, the medicalisation of painful menstrual periods seems to lag behind. This is likely an artefact of the historical notions related to menstruation as painful. The non-medicalisation of these entities leaves women with endometriosis unable to gain a

medical diagnosis. Positiong in the a-diagnostic category results in their waiting years without a diagnosis of endometriosis.

Remaining in the a-diagnostic category confirms that the diagnosis is uncertain, at least from the perspective of the patient.

> When the diagnosis is not certain, or when there is no diagnosis or explanation forthcoming, the patient is left to manage that uncertainty alone, sometimes taking on the role of the 'proto-professional', where they are required to actively 'participate in the process of being diagnosed and cured' (Novas and Rose 2000; Stockl 2007: 1557 in Price and Walker 2014).

For women in the a-diagnostic category, there is no 'diagnostic closure' (Street 2011); there is no limited differential diagnosis with a declared cause of disease. There is also less focused treatment provided, and access to the sick role (Parsons 1951) is less than what we expect to be associated with a diagnosed condition.

A. The A-Diagnostic Category and Endometriosis

The difficulty in obtaining the diagnosis of endometriosis has been clearly documented. The delays to diagnosis average about 7-10 years worldwide (Johnston et al 2015), and range from 12 years in the USA to 8 years in the UK and 6.7 years in Norway (Ballard et al 2006, Hadfield et al 1996, Husby et al 2003, Pugsley and Ballard 2007). This long delay to diagnosis exists despite the fact that women with endometriosis attend GPs frequently. These increased doctors' visits are often dismissed and linked to complaints of psychosomatic or functional origin (Johnston et al 2015). One reason for this delay is menstrual stigma, with both women and clinicians normalising endometriosis pain (Ballard et al 2006, Denny and Mann 2008, Manderson et al 2008, Markovic et al 2008, Seear 2009b, Santos et al 2012). In addition, clinicians tend to maintain a low index of suspicion when confronted with a woman who complains of pelvic pain. The result is that other causes of pain are prioritized before considering endometriosis (Johnston et al 2015).

The delay in diagnosing endometriosis has therefore been linked to both doctors and women (Ballard et al 2006, Manderson et al 2008), although much of the delay occurs after women have sought care (Husby et al 2003). Ballard et al 2006 in a study of women with endometriosis in the South-East of England found that out of 101 women, 20 consulted a GP five or more times before diagnosis. At the medical level, three factors may be at play: 1. The normalisation of pain by GPs; 2. The suppression of symptoms through medical treatment (hormones); and 3. The use of investigations such as ultrasonagraphy (scans) or measurements of non-specific biomarkers such as CA-125 to rule out endometriosis, despite their inability to do so (Ballard et al 2006). In addition, the belief by many clinicians that endometriosis does not present in teenagers may also increase time to diagnosis (Johnston et al 2015), with as many as 44% of women reporting symptoms of endometriosis to their doctors before age 20 and only 3.5% diagnosed before reaching 20 years of age (Arruda et al 2003).

Reasons for delays amongst women have been described and analysed by Manderson et al (2008). Women were found only to receive the endometriosis label successfully through four catalysts, termed 'circuit-breakers': 1. When other people such as partners or mothers encouraged help-seeking; 2. When their social roles were significantly disrupted; 3. When they experienced biographical disruption through, for example, inability to be a mother; and 4. When 'women's confidence in their interpretation of their embodied experience [held] greater power than the medical construction of their illness' (Manderson et al 2008: 528). These four 'circuit-breakers' allowed women's recognition that what they were experiencing was problematic and prompted their persistent search for care.

Patients in Denny and Mann's 2008 study felt there were two main negative attitudes adopted by GPs. The first was that patients' symptoms were either dismissed as 'just period pain' or as being psychological in origin. The second attitude reported by patients was the normalisation of symptoms that included being told that menstrual pain was normal and that 'you are unlucky to suffer from bad periods' (Denny and Mann

2008: 114). Such forms of dismissal of symptoms as psychiatric in origin or as 'normal' is typical of positioning in the a-diagnostic category.

Delay in diagnosis of endometriosis due to normalisation of menstrual pain is common (Denny and Mann 2008, Seear 2009b, Markovic et al 2008, Manderson et al 2008) because menstruation may be regarded as just a 'part of life'. With any pain from one's period seen as normal (Laws 1990, Seear 2009b), women may also normalise or dismiss each other's menstrual pain because it is a taboo subject (Laws 1990, Seear 2009b). This may be due to the presence of 'menstrual etiquette' – a concept taken from Laws (1990) that states that women's behaviour may be regulated 'by fear of social sanctions including derision, ostracism or criticism' (Laws 1990: 43). According to Seear (2009b), this was especially true regarding fear of ostracism by men. Her qualitative study of semi-structured interviews of twenty women with endometriosis in Australia found that women not only anticipated social sanction as a result of disclosure of menstrual problems but also were often reprimanded when they did so. Seear (2009b) suggested that the disclosure of menstrual problems might lead to difficulties because of men's view that it is 'an excuse to get out of duties that they believe women owe them' (Seear 2009b: 1124). In addition, she stated that the notion of menstrual etiquette led women to 'adopt a practice concealment', which was linked to the idea that 'making their menstruation visible may be ostracized' (Seear 2009b: 1124).

The result of finding oneself in the a-diagnostic category is significant. Markovic et al (2008) have explained that women with endometriosis experience two types of narratives with relation to the time spent seeking a diagnosis (often time spent in the a-diagnostic category): first, an endurance narrative in which women endure pain because they feel it is normal to suffer (a finding also found in this thesis in Chapter 7); and second, a contest narrative in which women begin to question and contest doctors' dismissal of their symptoms.

Denny and Mann (2008) reported that many endometriosis patients associated delay to diagnosis with symptoms not being taken seriously. This is an important observation,

as will become more obvious in forthcoming chapters. When diagnosed, the women felt vindicated for their persistence and often anger at their GP. Patients felt that lack of knowledge on the part of GPs regarding endometriosis was largely responsible for any delay in diagnosis. Furthermore, some patients reported that some GPs would repeat medical myths about endometriosis, such as a woman in her teens or early 20s was too young to have endometriosis, that having a baby would relieve the pain, and that having a hysterectomy would cure endometriosis with no possible recurrence of symptoms. Of course, there is potential here for patients to undergo unnecessary procedures as a result of medical advice based on myths.

B. Applications to Other Conditions

While I have applied the concept of the a-diagnostic category to endometriosis, I believe that this can be used in other long-term illnesses and diseases where patients struggle to receive a diagnosis or appropriate treatment despite a diagnosis. Lupus, like endometriosis, has clear diagnostic criteria with certain biological markers that indicate diagnosis of lupus. Yet despite this, 'diagnosis of lupus is characterised by the propensity for missed and mis-diagnosis' (Price and Walker 2014: 225). There remains a dispute as to when and how lupus should be diagnosed. Thus, patients' experiences of the condition become delegitimised, and their symptoms questioned. Without a definitive diagnosis, medical professionals often seek other explanations for the symptoms patients described. These alternative explanations, I argue, may fit into the a-diagnostic category I describe in endometriosis, as the clinicians described by Price and Walker (2014) not only often turned to psychogenic explanations for their patients symptoms, but in doing so they then found it difficult to shift their clinical gaze away from the patients' mental health. Psychiatry has offered fall-back explanations for these patients' symptoms, and other conditions (specifically lupus) were not considered (Price and Walker 2014).

Another clear application of the a-diagnostic category is in the realm of chronic pain. Eccleston et al (1997) suggested that 'the dominant discourse of pain has at its heart the "truth" that the pain had to be symptomatic (i.e. it must have a utility above suffering)

(Eccleston et al 1997: 700). With chronic pain, as there was no obvious utility, pain is often seen as 'in need of corroborating evidence' and both doctor and patient 'come to treat the investigation' of the cause with suspicion (Eccleston et al 1997: 700). The result is a situation in which patients are often stigmatized as 'uncooperative' or 'difficult' as the doctor might view the patient as 'imagining' the pain, suffering from a psychosomatic illness or 'attention-seeking' (Eccleston et al 1997: 700).

Good et al (1992) posited that with the concept of pain comes the categories of 'real' and 'unreal' or 'psychological' pain. Often, chronic pain is placed into this second category of 'unreal' or 'psychological' pain, as it no longer served a biological purpose. With regards to the concept of 'real' versus 'unreal' pain, the hospital gynaecologists in Selfe et al's (1998) study suggested that identifying pathology would validate pain as "real". However, they also added that an anxious patient might make the diagnosis difficult. Selfe et al (1998) tape-recorded focus group discussions among groups of gynaecologists, GPs, and patients with chronic pelvic pain. Both groups of doctors spoke of 'possible stress related and psychological influences of pain' (Selfe et al 1998: 217). This echoed Jones' (1988) article on doctor-patient relationships in endometriosis where she suggested certain patients are or can be addicted to pain.

Eccleston et al (1997), in comparing patients' and health professionals' understandings of chronic pain, found that medical professionals saw chronic pain as arising from patients' loss of control and bad habits. However, it is important to note that theirs is not the 'psychological' explanation seen above and often cited by chronic pain patients and endometriosis patients (Good et al 1992, Ballweg 1997, Griffith 2009). Here, health professionals agreed with statements such as 'The tendency to suffer from chronic pain is something a person may learn' and 'People become chronic pain sufferers because they manage pain badly' (Eccleston et al 1997: 704).

In addition, chronic pain was not considered to be a sign of illness or disease by the medical professionals agreeing with the following statement: 'People assume that medicine can cure everything; often the causes of chronic pain simply have no cure'

(Eccleston et al 1997: 705). This statement directly conflicts with patients who believed that there is a cause to their pain (Eccleston et al 1997). In contrast, patients strongly agreed with the statement 'there is always a physical cause of chronic pain even if doctors cannot diagnose it' (Eccleston et al 1997: 705). So, while patients looked to be disassociated from any guilt, blame, or responsibility for the pain they experienced, and even blamed the doctors for not finding a cause or a solution for the pain, the health professionals seemed to give the patients some responsibility for their pain.

This has also been reported by May et al (2000) who suggested that in patients with chronic low back pain, the uncertainty about the 'real' nature of their pain meant that '[t]he patient is confronted by an expression (that may be either implicit or explicit) of clinical doubt about their symptoms' (May et al 2000: 223). The responsibility then lay with the patient to convince the doctor both that the symptoms described an accurate representation of the pain and that the resulting disability was warranted based on the symptoms (May et al 2000).

Not only is chronic pain often linked to disbelief in any organic causes, it also then may be linked with a struggle by patients to receive a diagnosis that explains their symptoms. Patients with chronic pain and their families have been shown to be dissatisfied with the health care system. This may relate to a series of 'core conflicts' between health care professionals and patients suffering from pain (Good et al 1992: 8). These conflicts included distrust over pain assessment, disagreement about the influence of voluntary control of symptoms, and the issue of accountability (Good et al 1992: 8). The resulting frustration of both physician and patient with regards to the adequacy of therapeutic interventions fueled potential clashes (Good et al 1992). Such a situation appears to be similar to the a-diagnostic category, the associated notions of not being believed and the resulting struggles for validation and access to care reported by women with endometriosis.

VII. Biopower, Regulating, and Disciplining of Women's Bodies

In endometriosis, biopower limits women's access to the endometriosis label through mechanisms such as stigma and power dynamics in the clinic. At the same time, it contributes to the reasons women seek the label energetically. Michel Foucault's (1963, 1975, 1976, 1977, 2004) 'biopouvoir' or 'biopower' is a form of influence that controls and regulates citizens through biology. This is not a top down form of power but instead represents a power that is enforced through individuals and institutions. He separates the concept of biopower into: biopolitics (regulatory power) and disciplinary power, the first working at the population level and the second focussing on control over the individual body (Foucault 1976).

Well-known examples of biopower used by Foucault included sexuality. He suggested that masturbation negatively affected the individual body, which was a manifestation of disciplinary power. He also described the regulation of sexuality with masturbation seen to cause various illnesses and to limit the society's ability to reproduce (biopolitics or regulatory power). Foucault suggested that society had an interest in regulating reproduction through births (la naissance). He described the hysterisation (l'hystérisation) of women's bodies in *Histoire de la Sexualité I*, where women must assure the fecundity of the social body and have responsibility within the household to produce and guarantee the biologicomoral (biologicomorale) education of their children (Foucault 1976: 137). Women remain constrained and regulated by biopower around the control of reproduction and children. I present these examples among the many he presented throughout his publications, as they may be applied to endometriosis. The regulation of reproduction becomes key to the understandings of both menstruation and childlessness, as we will see in future chapters.

However, Foucault asserted that biopower (both biopolitics and disciplinary power) emerged in the 18th century. He described an historical shift from a model of government in which souveraineté (sovereignty) was central, with a 'souverain' who had

power over death and determined which subjects would die normally or because of punishment. As the shift occurred in the 18th century, the form of government turned to controlling and regulating behaviours. This he argued also became apparent around what he called the pathologisation of women's bodies which only began in the eighteenth century, where women's bodies became medical objects (Foucault 1977). For Foucault, a long history of medicine existed that considered women's bodies as the 'disease of man', 'fragile' and 'almost always ill'. The 18th century saw a shift to a stronger medicalisation of women's bodies (Foucault 1977), with emphasis on the woman's body as sick and weak.

Foucault has been used by many feminist authors to discuss the application to women of surveillance, regulatory power, and disciplinary power (Bartky 1988, Butler 1990, Sulik 2011a), as well as the associated resistance to such forms of biopower (Sawicky 1997). In endometriosis, biopower limits women's access to the endometriosis label and at the same time contributes to the reasons that women seek the label and want the label so strongly. However, this regulation (at the population level) and disciplining (at the individual level) of women's bodies appeared to have begun as long ago as the Hippocratics, who clearly set out women's bodies as intrinsically flawed.

The interplay between the multiplicities of endometriosis and the search for the one singular label becomes complicated by the regulation and disciplining of women's bodies through collective biopower. This occurs in several different ways. First, women with endometriosis continue to struggle against notions dating back to the Ancient Egyptians around women's bodies as fundamentally flawed (in comparison to men). Second, women's menstruation is currently seen as negative, highlighting women's lack of production (of children) (Martin 1987) and its largely taboo status (Delaney et al 1988). This may affect patients' ability to discuss their symptoms effectively and in a timely fashion. In addition, Van de Walle and Renne (2001) noted that throughout Western history a 'paradoxical notion of menstruation as a disease without which the body could not be healthy' has predominated. This has been coupled with the notion of fertility as central to the good health of women (Van de Walle and

Renne 2001). The current environment, it is argued, is one of 'involuntary childlessness [being] recognized as … one of the greatest forms of unhappiness and loss an adult woman might have to endure' (Thompson 2005: 55).

With the social persistence of negatively gendered understandings of menstruation, pain during menstruation is reflected in the struggles to determine specific diagnostic categories such as endometriosis. Endometriosis struggles to be separated from anything from dysmenorrhoea, to depression, something which reflects the current social understandings of menstruation, which have not changed much in centuries. Thus, such historical, negatively-gendered notions are strongly felt in the present and ultimately influence the understanding of endometriosis as a diagnostic category. So while the medicalisation of women's bodies remains relevant in the present day, with current theorists (Martin 1987, Larsen 2015, Martel 2014, Sawicki 1991) emphasizing the present-day medicalisation of women's bodies, I argue that menstruation remains relatively non-medicalised which allows period pain to be considered normal.

This struggle for one label remains strongly evident around gendered notions of endometriosis, with the disease, menstruation, and the uterus placing women's bodies as abnormal, unruly, and in need of taming. I begin to address these matters in Chapter 3 where I examine the historical underpinnings of menstruation as being intrinsically painful, as well as notions around the uterus as 'monster' and 'unruly', concepts that study participants visually represented. Such notions continue and can be seen in Chapters 4 and 5 where women look to access care only to be told it is normal to have such levels of pain, meaning they find themselves in the a-diagnostic category.

Such regulating and disciplining of women's bodies contributes to the eventual multiplicity of endometriosis, creating greater diagnostic uncertainty and more 'differential diagnoses' such as 'normal period pain', 'depression', or 'anxiety', and at the same time to women's struggle against the multiplicity of endometriosis. It is the view of menstruation as intrinsically painful, the associated expectation that women not complain, and non-completion of expected life tasks that leave women feeling

insufficient. This gendered rhetoric, which limits who can or will be able to gain access to the endometriosis label, plays out as the regulating and disciplining of women's bodies. This is particularly evident in Chapter 7 where I examine how forms of stigma (be it around menstruation, childlessness or sex) impact on the behaviour of women, ultimately limiting their ability to access medical care for endometriosis.

At the same time, this regulating and disciplining of women's bodies determines who is given the endometriosis label, with teenagers in particular struggling to access care because menstrual periods 'are meant to be painful'. In addition, treatments offered are limited based on expectations by doctors of women's reproductive output or productivity, with women who are voluntarily childless being told 'they may change their minds' and women who are involuntarily childless being 'taken more seriously'.

VIII. Impact on the Clinical Visit

Both the multiplicities of endometriosis and the simultaneous struggle for one label can be seen in nearly every realm, but becomes particularly relevant in the clinic, where women with endometriosis seek to push their doctors to provide a diagnosis or treatment despite being stuck in the a-diagnostic category. Often in spite of having a diagnosis of endometriosis, women fear being given another label and moved into the a-diagnostic category, something they often experience as not being believed. From time to time, I encountered women who had indeed been diagnosed with endometriosis. However, their pain was not responding to the usual treatment. At that point clinicians seemed to conclude that the current pain was not due to endometriosis. In some cases, this led to a reconsideration of the patient's pain history, with the conclusion that the symptoms were not due to endometriosis and that endometriosis might be an incidental finding. The ultimate effect was that the women's complaints were not due to endometriosis and these women were found themselves in the a-diagnostic category again with their symptoms often put down to psychiatric illness.

The lack of a distinct label/diagnosis leaves women (with endometriosis) feeling powerless, and grieving. This is then reflected in a clear struggle within the clinic

where women look for ways to assert the 'truthfulness' of their suffering, and the legitimacy of their pain. This is then counterbalanced by health professionals (both nurses and doctors) who often feel at best uncomfortable with patients' efforts to be 'taken seriously'. The result is a mutually escalating 'tension' similar to what Kleinman (1988) has described in a chronic pain clinic. The multiplicities of endometriosis play out in the clinic in terms of treatment plans, while the multiple enactments also often ironically serve to limit who can be considered to have an endometriosis diagnosis. The dyadic relationship of doctor and patient in the clinic does not remain isolated (Elwyn et al 1999, Rapley 2008, Mol 2002). Nurses, enactments of endometriosis, and the a-diagnostic phenomenon all impact the doctor-patient relationship.

IX. Conclusion

Mol presents a view of medicine that seeks to include both biomedicine and psycho-social medicine within medical practice. She argues for medicine to include within it the multiplicities of disease. With this, she hopes we will improve patient care and move away from the notion that biomedical understandings take precedence over lay meanings of disease.

The endometriosis diagnosis struggles to remain fixed but is still contested, in large part because of the multiplicities inherent in the disease and the clinical practices associated with it. However, endometriosis' contested notions contribute to its multiplicity and at the same time elucidate reasons why women seek and find the label of endometriosis so important. This multiplicity and its associated a-diagnostic category lead women to focus even more on its singularity, on one label. Yet, perhaps because of the very multiplicity of endometriosis enactments, after a long struggle for the diagnostic label, women often report that acquisition of the label did not provide what they were expecting. In my study, the label itself did not often meet the hopes and expectations of the women.

Mol's (2002) significant contributions allow us to consider endometriosis through a different lens, one where the multiplicities of endometriosis (its biomedical side) and its

other sides are highlighted. Her ideal situation in endometriosis care would be one which combines both the many aspects of endometriosis from the sufferer's point of view but also the biomedical notions that allow for medical practice and treatment of the disease. Without question, we should strive for clinicians to be aware of the other multiplicities of endometriosis in their work. But I fear in endometriosis, we have not yet reached such an enlightened form of medical practice. Instead, the multiple enactments of endometriosis, which are so clearly present, similar to Mol's (2002) example of atherosclerosis, serve to create a 'messiness' or uncertainty that trouble clinicians.

Women struggle to receive the endometriosis label after being stuck in the a-diagnostic category for an extended period, with some women remaining without a diagnosis for twenty years. Even after receiving the diagnosis, women still may effectively be moved back into the a-diagnostic category when their symptoms do not respond to treatment as the doctors had hoped.

Ultimately, an important objective of my work is to improve the care of women with endometriosis. Examining the multiplicities of endometriosis, the different ways of enacting the diagnosis, the times when the diagnosis seems unstable, and the unnecessary suffering that characterizes assignment to the a-diagnostic category should allow a clearer picture of the difficulties that interfere with the optimal care of women with the disease.

CHAPTER 2

Methodology

I. Introduction

In the previous chapter, I set out the theoretical framework that undergirds this study. In this chapter, I examine the methods used in this thesis. This was an ethnographic study that took place in the North East of England from June 2013 through August 2014. I examined the differing narratives surrounding endometriosis told by doctors and by women with the disease to understand better how the contrasts affect the relationship between doctors and patients in the study. I focussed on the following four categories of individuals in order to access the multiple enactments of endometriosis: gynaecologists, nurses in the gynaecology clinic, health professionals in a chronic pain management clinic, and women with endometriosis. I utilized a variety of methods including: Interviews (semi-structured and informal), participant observation, questionnaires, textual analysis, and visual analysis of data. For clarity, I begin this chapter by presenting the research participants and then move on to specific details about the methods used.

II. Research Participants

There were four separate categories of participants involved in this study: gynaecologists (consultants and registrars), nurses working in the gynaecology clinic, health-professionals from a chronic pain management clinic (including doctors, psychologists, and nurses) and women with endometriosis or with symptoms potentially explained by endometriosis. Women with endometriosis were further divided into three groups: 1. members of a local support group, 2. members of a national support group, and 3. patients recruited through a gynaecology clinic. The table on the following page outlines the groups and methods used for each category.

A. Consultant Gynaecologists

The consultant gynaecologists enrolled in this study each participated in a semi-structured interview regarding past experiences with endometriosis or patients who have presented with symptoms consistent with possible endometriosis. Consultant

gynaecologists were also observed seeing patients and speaking with registrar gynaecologists and nurses. In addition, several informal interviews were undertaken.

Table 2.1: Methods Used and Number of Subjects in each Subject Group.

Subject Group	Method	Number of Subjects
Consultant Gynaecologists	• Semi-Structured Interviews • Informal Interviews • Participant Observation	5 5 3
Registrar Gynaecologists	• Informal Interviews • Participant Observation	15 15
Nurses from the Gynaecology Clinic	• Informal Interviews • Participant Observation	5 5
Pain Management Clinic Team Members: Consultants, GP, Psychologists, Nurses	• Semi-Structured Interviews	10
Patients – from Support Group	• Semi-Structured Interviews • Informal Interviews • Participant Observation	15 20 20
Patients – from Clinic	• Semi-Structured Interviews • Informal Interviews • Participant Observation	4 35 35
Online Sources	• Online Textual Websites (ESHRE, NICE Guidelines, Endometriosis UK, SHE Trust, Facebook) • Online Visual Websites (Facebook, Pinterest)	5 Main Websites 2 Main Websites
Meetings: World Congress on Endometriosis/ Million Woman March for Endometriosis	• Participant Observation • Informal Interviews	50
Patients National Support Group	• Questionnaires	10

B. Registrar Gynaecologists[1]

Registrar gynaecologists were observed both before, during, and after their visits with a patient with endometriosis or possible endometriosis. Additionally, informal interviews of the registrar gynaecologists were undertaken often after a clinic visit, when they were observed writing the medical note and recording the letter to the patient's General Practitioner. Registrar gynaecologists were also observed in their interactions with nurses, consultant gynaecologists, and other registrar gynaecologists.

C. Nurses in the Gynaecology Clinic

Five nurses were included in the participant observation of the clinic staff. One of these was a matron and one other was a ward sister. They were observed throughout the clinic time (3-4 hours) once a week. Notes were taken regarding their interactions with other nurses, doctors, and patients. In addition, I undertook informal interviews with the nurses to clarify their roles in the clinic and to gauge their thoughts on endometriosis patients as a group.

D. Chronic Pain Management Health Professionals

Chronic Pain Management Health Professionals underwent one semi-structured interview for between 30-60 minutes. I posed questions about their perception of issues related to the patient experience of endometriosis and to the inner workings of the chronic pain clinic.

E. Patients

I recruited patients either through their local support group, the national support group or through their gynaecologist. I describe these groups below. Patients recruited from

[1] Please note that at the time I was conducting fieldwork in the clinic there were 2 GP trainees rotating through the clinic. However, they were acting as gynaecologists and not as general practitioners.

[2] I have found different articles on the history of menstruation, dysmenorrhoea and endometriosis all use the same examples to

the local support group were on the whole educated women with at least one university degree. In contrast, patients recruited from the clinic usually were not university educated. Patients recruited from the national support group seemed to be a mixture of more or less educated women.

1. Local Support Group

Patients recruited through their local support group took part in semi-structured interviews, participated in support group meetings that I observed, and wrote in an online Facebook group. Not all patients recruited from the local support group were involved in all of the above-mentioned activities. Instead, some took part in all and others took part in only some of this aspect of my fieldwork; I shall provide further detail in the relevant sections.

a. Semi-Structured Interviews

Interviews lasted from an hour to two hours, with most lasting about one and a half hours. The interview sought to develop a narrative of the patient's journey through the medical system. I attempted to ascertain the patient's view on what distinguishes a positive doctor-patient interaction from a negative one. Participants were encouraged to add any information they thought was relevant to their experience of endometriosis.

b. Support Group Meetings

I attended and observed support group meetings throughout a one-year period. As these meetings took place on average every two months, I attended six meetings. Each meeting lasted approximately an hour and a half, with some lasting slightly longer as extra activities were included.

c. Online Facebook Group/Online Forum

The members of the support group only used this online group occasionally, with approximately one post every week. Any posts written in this online forum were analysed thematically.

2. National Support Group

The patients recruited from the national support group were sent questionnaires by email. In addition, patients who were members of the National Support group took part in the Million Women March for Endometriosis in London on March 13, 2014 where I undertook approximately five hours of participant observation.

3. Gynaecology Clinic

Each patient recruited through her gynaecologist was followed in a medical visit for endometriosis or symptoms suggestive of endometriosis. In addition, I read her medical file and analysed it thematically. Thirty-five patients were asked to discuss endometriosis and their experience with the medical system in the form of an informal interview often lasting for approximately 10 or 15 minutes. In addition, five of these 35 patients underwent a semi-structured interview lasting between 45 and 90 minutes.

Recruitment through the gynaecology clinic was slow, with two women recruited at each clinic, not unlike what Wray et al (2007) describe as continuous patient recruitment for their study on gynaecological cancers in Australia. I usually saw women recruited through the support groups several times, as I generally met them first in a support-group meeting and then saw them again later for an interview. In contrast, I may have only seen the clinic-recruited women once or very rarely twice, usually in quite formal settings. This means that women recruited from the clinic may have interacted with me in a more formal way, and perhaps they felt less willing to share information. This may be reflected in the length of the interviews with women from the clinic, who usually spent 45 to 90 minutes speaking to me as opposed to between 60 and 120 minutes for the other women. This difference in interview length may have occurred because I often interviewed women in the clinic right after their visit, without much pre-warning. These women did not have as much time set aside for the interview.

III. Methods/Data Analysis

Overall, an ethnographic approach was utilized in this study. Ethnography involves the researcher's participation in the daily lives of her participants, with participants studied in everyday contexts, for a prolonged time-frame, as well as observing and listening to what transpires (Hammersley and Atkinson 2007). Information is gathered from multiple sources including documents, formal and informal interviews (Hammersley and Atkinson 2007). Five methods were used in this thesis: semi-structured interviews, informal interviews, participant observation, content analysis of text and analysis of visual data. The research fields included the internet, a gynaecology clinic, a pain clinic, and support group meetings.

The data collected by interviews, questionnaires, and participant observation were transcribed and where appropriate, examined thematically. Thematic analysis involves identifying patterns or themes in the data (Vaismoradi et al 2013). I used an inductive approach to all forms of data, looking specifically at what themes appeared to come out of the data (Nowell et al 2017). Data were coded and then split into specific themes. The data were then re-read to look for more specifics, then creating sub-themes. The themes and associated data were then further analysed with links to the theoretical framework I set out in the last chapter.

A. Semi-Structured Interviews

Semi-structured interviews are considered to 'follow a general script and cover … a list of topics' while remaining 'open ended' (Bernard 2006: 212). Semi-structured interviews remain 'based on the use of an interview guide. This is a written list of questions and topics that need to be covered in a particular order' (Bernard 2006: 212). I undertook semi-structured interviews with consultant gynaecologists, chronic pain management health professionals, and women with endometriosis. They were all audio-recorded, and then I transcribed and analysed the recordings for recurrent themes.

For specific interview guides please see the Appendices. Information presented in this thesis deriving from semi-structured interviews has been denoted with the letters SSI.

I used semi-structured interviews to ascertain what consultant gynaecologists believed to be the narrative surrounding endometriosis. This involved describing their experiences with endometriosis patients, or women with suspected endometriosis such as those who presented with complaints of chronic pelvic pain or infertility. I explored what consultant gynaecologists felt were the specific problems of this subset of patients, as well as the gynaecologists' understandings of patients' experiences. Finally, questions addressed what consultants might teach general practitioners (GPs) or other gynaecologists about endometriosis.

I also employed semi-structured interviews with women with endometriosis. For each individual, the interview typically began with her endometriosis history, when she first experienced symptoms of endometriosis and how and when she received the diagnosis of endometriosis. I tried to understand how endometriosis affected their lives, including how it influenced relationships with co-workers, friends, and family members. I posed questions about previous interactions with medical professionals, including GPs and gynaecologists. The patient interview also addressed quality of life and mental health factors. I added other questions to clarify specific subjects that women had brought up in the interview. For example, many women discussed gendered understandings of endometriosis. Thus, I began to ask whether gender affected understandings of the disease.

Health professionals engaged in the management of chronic pain also participated in semi-structured interviews that focused on their experiences of endometriosis patients, what they saw as specific problems related to the condition, as well as their thoughts about patient experiences of the condition. In addition, I asked them about what they thought gynaecologists and GPs should consider when treating women with endometriosis.

B. Questionnaires

Online, self-administered open-ended questionnaires were sent to women from the national support group (Bernard 2006). Each woman received her questionnaire by email, and she then returned the completed questionnaire to me. The questionnaire covered the same questions as the semi-structured interviews used with women with endometriosis and discussed above. Data presented in this thesis from questionnaires have been identified with the letter Q.

C. Informal Interviews

I carried out informal interviews with three main groups of participants: patients, doctors, and nurses. Patients were interviewed informally after a support group meeting or while at the clinic. Doctors and nurses were informally interviewed during the clinic time. Doctors and patients who attended the World Congress on Endometriosis Meeting and the Million Women's March for Endometriosis were also informally interviewed. In this thesis, I have labelled information derived from Informal Interviews with the letter I.

D. Participant Observation

The roles of participants in ethnography have been divided into the complete participant, the participant-as-observer, the observer-as-participant, and the complete observer (Flick 2002). These four examples represent a continuum for the researcher with regards to her fieldwork. The complete participant does little observing and the complete observer maintains a distance from the field in question (Flick 2002). Within the gynaecology clinic, my role was not to provide clinical care or to act as a patient. I therefore did little 'participating' in the doctor-patient interaction. I was mostly there as an observer. However, since the behaviour of the gynaecologists and patients did change in my presence, with gynaecologists specifically talking to me about the interaction, and patients staying later to participate in an interview, I did undertake more

than simple observation (Flick 2002). Thus, I suggest that I took on the role of observer-as-participant in the gynaecology clinic. I was a participant observer in several settings including the support group meetings, the Million Woman March for Endometriosis, the 11th World Congress on Endometriosis, and The Mad Pants Tea Party. Information utilized in the thesis deriving from participant observation fieldnotes has been denoted with the letter F. I approached my participant observation in a disciplined fashion so that I would not engage in the research with preconceived notions. I wrote down what the participants said, and what I saw.

1. The Gynaecology Clinic

The National Health Service (NHS) was founded in 1948, and provides free healthcare to all those resident in England at point of contact with the exception of some charges such as prescriptions (which remain paid for at a set rate per prescription which is currently at 8.80 pounds) or dentistry charges for example (NHS website 2018). These extra charges are different in each country of the UK with Scotland, for example, not charging for prescriptions (NHS website 2018). It is within the NHS that my fieldwork in the gynaecology clinic was undertaken.

I carried out participant observation in a local gynaecology clinic (part of the NHS) from June 2013 through September 2014. The clinic was not a specialised endometriosis clinic, but rather a general gynaecology clinic that served not only women with endometriosis but also women with other gynaecological complaints ranging from vaginal discharge to potential cancer diagnoses. The clinic was located in a large regional hospital with a maternity ward reporting 5700 births a year. I attended the clinic usually one morning and two afternoons a week depending on the clinics set up that week. From time to time, general gynaecology clinics were not scheduled. Reasons for this varied but had to do with consultants' timetables and holiday schedules.

The clinic itself was located in one wing of the hospital that was dedicated to clinic care. However, the physical location served several clinics, including a rheumatology

clinic at other times. Thus, the clinic, in that sense, did not feel like a settled entity, but rather was set up and then dismantled after every four-hour session. For example, the nurses' station was not a dedicated physical space, but was set up either in the hallway (the afternoon session) or in an extra clinic room with a patient's bed serving as the table for the medical notes (in the morning).

I sat in on an average of two gynaecologist-patient visits per clinic. During the visits, I took notes about the nature of the encounters. I considered the interaction between gynaecologist and patient – whether it appeared positive or strained, what information was addressed, when patients were offered laparoscopy (keyhole surgery) and what was even considered endometriosis. Other topics that eventually came up involved gendered notions around endometriosis, how historical notions of endometriosis and power dynamics affected interactions in the clinic.

I sat in the nurses' station where notes were kept for the doctor's review. It was here that the nurses spent time speaking to each other about patients, doctors, and other colleagues. Doctors also came while awaiting patient arrivals and to see patient notes. Thus, I was able to overhear discussions concerning patient care, but also discussions on relationships between registrars, consultants, and nurses. As the ethics around this are worth raising, I discuss this in more detail in the ethics section.

2. Support Group Meetings

I carried out participant observation at local endometriosis support group meetings from August 2013-May 2015. These meetings generally took place every two months either on a Saturday from 11:30am to 1pm or on a weekday evening. The location of these meetings varied. Several meetings were held in the evening at a local hospital and were attended either by the local gynaecologist who focused on endometriosis or by the specialist endometriosis nurse who worked with him. This allowed women with endometriosis to ask specific medical questions about their disease. However, the majority of the meetings were held Saturday mornings at various coffee shops to allow

for a '*more relaxed environment*', as the head of the group, Alice, explained. The location varied because the members of the group lived in several different counties.

3. The 11th World Congress on Endometriosis

I attended the international endometriosis meeting held in Montpellier, France in 2011, with 1294 delegates from 73 countries. There were 102 oral presentations, 6 keynote lectures, and 374 poster presentations (World Congress on Endometriosis 2011). Attendees included researchers (both clinical and basic scientists), and medical professionals, the majority of whom were specialist gynaecologists. Women with endometriosis were also present. Many of the women were part of their local and national endometriosis associations, while others ran either local or national groups. I attended biomedical talks on clinical care of endometriosis and on patient viewpoints. This allowed me to gain insight into current debates related to endometriosis.

I spent considerable time over dinner in conversation with about 20 women with endometriosis. I also attended an evening event organized by women with endometriosis. This fostered a more informed understanding of the endometriosis movement. I attended a day-long discussion that focused on the creation of endometriosis guidelines; this gave me rare insight into guideline formation. This discussion group comprised approximately 40 individuals, including the heads of the World Endometriosis Society, national support-group leaders, and directors of biomedical research on endometriosis.

4. The Million Women March

The Million Women March for Endometriosis (March 13, 2014) was held at the Kensington Gardens in London. It lasted approximately four hours and was attended by women with endometriosis and family members including male partners and mothers. During the march, I held discussions with participants and made observations while I walked in the march wearing Endometriosis UK attire. After the march, I spent some time with two female participants and had lunch and walked around London with them.

5. The Mad Pants Tea Party

I engaged in participant observation at the Mad Pants Tea Party (September 27, 2014) in a local village hall in the North East of the UK. This was organised by the local support group and attended by its members as well as individuals from neighbouring communities.

E. Textual Analysis of Sources

I undertook content and textual analysis of three different types of written text or data to determine trends and patterns used (Vaismoradi et al 2013). Sources of this written information were: patient medical records; sources provided by two endometriosis support organisations (SHE Trust and Endometriosis UK); and clinical practice guidelines on endometriosis accessed from online sites (ESHRE and NICE). Data from online support group posts, which were primarily linked to visual representation of endometriosis, are considered in section F of this chapter. I later examine them thoroughly in several chapters. Those data are labelled with the letter O.

1. Patient Medical Records

Reading patient medical records was allowed by the regulations in my NHS ethics form. I was permitted to access files only if women specifically gave consent on their ethics agreement form. As a result, I was obliged to meet with the women and have them agree to participate in the study first. Only then could I access the medical files. However, as the files were only pulled for a medical appointment, I was restricted to viewing the medical files during clinic hours. This sometimes resulted in a very rushed encounter with files that often had several hundred pages that were divided into multiple volumes. This information was analysed thematically, with the intent of understanding the patient's history with endometriosis.

2. The SHE Trust and Endometriosis UK

I examined the websites of both the SHE Trust and Endometriosis UK, the two main endometriosis support groups in the UK. Thematic analysis of these data allowed me to understand more about the role of the endometriosis movement and some of the main organisations involved in the UK. I have examined in Chapter 9 the different roles these two organisations play.

3. Clinical Practice Guidelines

Another important textual source are guidelines linked to care practices in the UK. I note that endometriosis guidelines vary around the world, with differences in Canadian as well as US guidelines, for example, but these are not used in the UK. I have considered two guidelines utilized in the UK: the ESHRE guidelines and the NICE guidelines. I have not included the Royal College of Obstetrics and Gynaecology (RCOG) guidelines as they have deferred to the ESHRE or NICE guidelines since their 2006 guidelines. While these separate guidelines exist simultaneously to guide treatment and diagnosis of endometriosis, they also often provide contradictory advice or information. These contradictions that surround endometriosis present some problems for medical practice.

a. ESHRE Guidelines

The European Society of Human Reproduction and Embryology (ESHRE) was founded in 1985 to 'promote interest in, and understanding of, reproductive biology and medicine' (ESHRE 2013: 2). Its main roles are to facilitate research and dissemination of results as well as to improve clinical practice through teaching and guidance on safety and quality assurance (ESHRE 2016). In producing guidelines, the society sought 'to provide clinical recommendations to improve the quality of healthcare delivery within the European field of human reproduction and embryology' (ESHRE 2013: 2).

ESHRE sees the role of its endometriosis guidelines as providing clinical recommendations, which will 'aid healthcare professionals in everyday clinical

decisions about appropriate and effective care of their patients' (ESHRE 2013: 2). However, ESHRE reiterates that the role of these guidelines remains one of guidance, explaining that guidelines do not replace in any way clinical judgement in diagnosis or treatment. Nor do they aim to 'establish a standard of care' (ESHRE 2013: 2). They go on to state that:

> Ultimately, healthcare professionals must make their own clinical decisions on a case-by-case basis, using their clinical judgment, knowledge and expertise, and taking into account the condition, circumstances, and wishes of the individual patient, in consultation with that patient and/or the guardian or carer (ESHRE 2013: 2).

These guidelines further say that:

> ESHRE makes no warranty, express or implied, regarding the clinical practice guidelines and specifically excludes any warranties of merchantability and fitness for a particular use or purpose. ESHRE shall not be liable for direct, indirect, special, incidental, or consequential damages related to the use of the information contained herein. While ESHRE makes every effort to compile accurate information and to keep it up-to-date, it cannot, however, guarantee the correctness, completeness and accuracy of the guideline in every respect (ESHRE 2013: 2).

This disclaimer aims to distance ESHRE from any direct responsibility in clinical care, giving clinicians the right to differ from this guidance, and at the same time ensuring that ESHRE is not found legally responsible for any medical decisions.

The current ESHRE guidelines 'Management of women with endometriosis' were published in September 2013. This ninety-five page document covers topics such as the diagnosis of endometriosis, treatment of endometriosis-associated pain, treatment of endometriosis-associated infertility, medically assisted reproduction, menopause in women with endometriosis, asymptomatic endometriosis, prevention of endometriosis, and endometriosis and cancer. Further sub-sections include: symptoms and signs of endometriosis, clinical examination in the diagnosis of endometriosis, and medical technologies in the diagnosis of endometriosis.

The ESHRE guidelines, while presenting biomedical understandings around endometriosis, directly address some of the historical vestiges I examine in Chapter 3,

such as delayed pregnancy causing endometriosis, and pregnancy and hysterectomy being cures for endometriosis. ESHRE tends to present views that question or contradict ideas such as: notions of cure relating to pregnancy or hysterectomy; the usefulness of prescribing hormones in endometriosis treatment; non-visualisation of endometriosis during surgery eliminates endometriosis as a potential diagnosis; and teenagers or post-menopausal women may not be considered to have endometriosis.

b. NICE Guidelines

The National Institute for Health and Care Excellence (NICE) was founded in 1999 by the UK government. Its goal was to present evidence-based recommendations on medical conditions and associated treatment protocols (Moncrieff and Timimi 2013). According to its charter, NICE is:

> the independent organisation responsible for developing national guidance, standards and information on providing high-quality health and social care, and preventing and treating ill health. NICE guidance helps health, public health and social care professionals deliver the best possible care based on the best available evidence – (NICE 2017:1).

NICE guidelines have become internationally recognized and are often considered to 'represent … the gold standard of medical practice' (Moncrieff and Timimi 2013: 59). NICE's primary responsibilities involve evaluating new drugs and treatments, providing evidence-based guidelines on medical conditions,

> provid[ing] guidelines on how public health and social care services can best support people, and provid[ing] information services for those managing and providing health and social care (Cancer Research 2016).

The treatments that NICE includes in its guidelines are used to determine which treatments the NHS may fund and which protocol doctors within the NHS are expected to use.

> Once NICE issues its guidance, NHS trusts must find the money to make those drugs or treatments available. NICE doesn't give any extra money, or advise on how to find the money (Cancer Research 2016).

In addition, NICE oversees the quality and outcomes framework (QoF), 'a voluntary incentive scheme for GP practices in the UK,' which helps determine which treatments are given and when patients are referred to specialists (NICE 2016 QoF).

> By overseeing the process of developing and reviewing performance indicators for the QoF, we ensure that the principles behind our recommendations are reflected in the indicators. This can encourage the implementation of guidance and lead to improvements in care across the UK (NICE 2016 QoF).

The General Medical Council suggested that 'doctors should take account of clinical guidelines published by established organisations with appropriate expertise, including those by NICE' (Dickson 2015). NICE has been criticized for not including contradictory evidence in their guidelines on depression, for producing guidelines that 'do not reflect the evidence presented' (Moncrieff and Timimi 2013: 62), and for not acknowledging the complexities of labeling and the social construction of disease in ADHD and depression. At the same time, it has been suggested that NICE guidelines are becoming 'increasingly complex and impractical and risk losing the confidence of GPs'. For example, 'NICE has found itself in direct and public conflict with the BMA (British Medical Association) over its statins advice'. Concerns have also been raised over its asthma guidelines (Pulse Today March 2015). In July 2015, the BMA stated that:

> We are concerned that NICE is proposing to publish guidance which contradicts most of the recommendations made by the joint British Thoracic Society/SIGN guidance on the diagnosis, monitoring and management of asthma which was published in October 2014 (Pulse Today July 2015).

The NICE guidelines on endometriosis examined in this thesis were published in 2014. Those guidelines are:

> largely based on guidelines from the Royal College of Obstetricians and Gynaecologists, The investigation and management of endometriosis, and the European Society of Human Reproduction and Embryology guideline, Management of women with endometriosis (NICE Right Topic 2016).

However, despite their apparent link to the RCOG guidelines and the more recent ESHRE guidelines, the NICE guidelines contradict those guidelines at times. In addition, the use of the RCOG guidelines when the RCOG has replaced its own

guidelines with the ESHRE guidelines is puzzling. Because the 2014 guidelines were in the process of being revised with an expected publication date in 2017, I have additionally looked at the most recent NICE endometriosis guideline scope, a summary of the topics they plan to discuss in the 2017 guidelines. For the 2017 guidelines, NICE made clear that it 'would consider similar areas to the ESHRE guideline but in the context of NHS-commissioned healthcare, and will include consideration of cost as well as clinical effectiveness' (NICE guideline scope 2016: 9). Therefore, in the context of the NHS, cost becomes a major consideration in the production of new endometriosis guidelines.

In notable contrast to the ESHRE guidelines, the NICE guidelines continue to link endometriosis to specific notions of womanhood, with suggestions that delayed pregnancy is a risk factor for endometriosis, that endometriosis is a disease that begins in a woman's twenties, and cannot affect a post-menopausal woman nor a woman who has had a hysterectomy. Such notions limit who can be diagnosed with endometriosis while simultaneously directly contradicting ESHRE's suggestions of the opposite.

Data from the clinical guidelines were analysed thematically to understand the enactment of endometriosis through the guidelines. This was then compared to how endometriosis was enacted in the gynaecology clinic. For more information, please see Chapter 5.

F. Visual Analysis of Sources

I analysed visual representations as found on several different websites (all open-access) from June 2013 to April 2016. These primarily included Facebook and Pinterest. Less frequently, I also used images found by searching key words such as 'endometriosis' or 'endometriosis awareness' in Google Images. The first set of data consisted of uploaded art made by endometriosis sufferers to represent endometriosis and their experiences with the disease. The second set of visual data represented images that were already on the internet and were used by members of various

endometriosis-related websites to represent endometriosis. In large part, this information involved not only visual images but also interspersed text.

I performed content analysis of both the visual data and the accompanying text as I was interested in the meanings endometriosis sufferers attached to the images they either created or posted. To do this, I examined not only the images themselves, but what the women wrote about why they posted the images or what they felt in seeing them, as well as hashtags they used. The text attached to the art allows us to understand better what sufferers were expressing through the images. Thus, I could 'attend not only to the internal ''meanings'' of an image, but also to how the image was produced and how it is made meaningful by its viewers' (Pink 2003).

At the end of the thesis in a section entitled 'Figure References', I have listed the references for the images I have used. I have included the name of the artist whenever possible.

G. Feminism, Ethnography, and Interviews

Feminist qualitative research analyses 'women's experience and the material, social, economic, and gendered conditions that articulate the experience' (Olesen 2000: 228) and seeks to 'find and express women's voices' (Olesen 2000: 231) from their own point of view (Reinharz and Davidman 1992). Feminist research is said to focus on power relations between the researcher and the researched with early feminist research looking for non-hierarchical relations (Skeggs 2001). However, this notion has since been dismissed as difficult to implement, and thus, many feminist researchers now acknowledge the power differentials that do exist (Skeggs 2001). Women's voices must retain their presence and their meaning without distortion or exploitation (Olesen 2000). I have allowed women to speak for themselves, both through the interviews and questionnaires, but also through the images they have posted online.

IV. Inclusion/Exclusion Criteria

As previously stated, there were four main categories of participants in this study: gynaecologists, nurses working in the gynaecology clinic, health professionals of the chronic pain management clinic, and women with endometriosis or suspected endometriosis. Originally, I set out to include in the study only female patients aged 18 and older with a history of either diagnosed endometriosis or undiagnosed chronic pelvic pain. A patient was to be excluded from the study if she had a known cause for her chronic pelvic pain other than endometriosis. The decision as to whether patients were to be included in the study was finally a more difficult issue than originally thought. Defining who might be included as a patient with endometriosis or a patient with suspected endometriosis proved to be a relatively complicated task. For example, one patient was considered to have endometriosis no longer, as she was 'cured' after her hysterectomy. In addition, patients with symptoms of dyspareunia, chronic pelvic pain, or infertility were not necessarily considered to have endometriosis, although the possibility existed. Loosening the inclusion/exclusion criteria made it possible for me to hear a broader spectrum of stories from women who were struggling with the disease, and at different phases in the disease's development.

I note that this study unfortunately did not include women of colour (known as BAME in the UK denoting Black, Asian, and Minority Ethnic) with the exception of women who posted online data. This of course is likely due to the region in which I conducted my fieldwork (the North East of England) where only 4.7% of the population identifies as BAME (Business in the Community 2011). However, this may also reflect the broader notion that minority women are not seen as potential patients with endometriosis. This concept has historical links to ideas of endometriosis as a 'career woman's disease' (Capek 2000), which I address later in the text. With the exception of online, women in this study identified as cis, heterosexual women. This is related to the problem that patients with endometriosis are assumed to be heterosexual 'women', a topic I begin to address in Chapter 9. The fact then that endometriosis has long been considered a disease of white, educated (Capek 2000), and heterosexual women is problematic and misleading, and makes it difficult to include in research patients who

do not fit into these molds. For example, academic research on 'women' with endometriosis has largely been inattentive to black women, with the exception of a review article (Kyama et al. 2007) and an article by Denny et al (2011) on the experiences of women of colour in the UK. I found no studies on non-cis women or patients with endometriosis who consider themselves men. In my research sample, these groups were essentially unrepresented. In my last chapter, I begin to address these matters through data from online sources. Accessing such groups of patients online may be easier as the numbers are of course higher. In addition, such groups of patients may join online groups and therefore may be found in one place. Also, especially when it comes to sexuality or gender matters, online may provide a safer space with increased anonymity to address potentially stigmatising and sensitive topics. While I did not specifically search for patients who fit these underrepresented categories in my research online, I still found these participants more easily accessible online. I do hope that my future research will include such patients.

Regarding the doctors involved in this study (consultant gynaecologists, registrar gynaecologists and chronic pain consultants), the inclusion criteria were to be that he or she was a member of the Royal College of Obstetricians and Gynaecologists or of the Royal College of Anaesthetists, that they practiced in the North East of England and that they were practicing within the NHS. In addition, consultant gynaecologists were required to treat endometriosis in their practices. However, doctors were included if they were part of the clinics in which I was doing fieldwork. I was unable to check if doctors were members of the Royal College of Obstetricians and Gynaecologists or of the Royal College of Anaesthetists. Instead, their presence in the clinics became the inclusion criterion for this study.

V. Research Ethics

I sought research ethics approval from both the Durham University Department of Anthropology and the National Health Service (NHS). Seeking ethics approval from the former was a fairly simple process. Obtaining the necessary approval from the NHS was more complicated. This involved 10 months of work and of filling in forms that for

the most part seemed skewed to a biomedical study. The NHS ethics approval included only the parts of the study that were to take place within the NHS, specifically data collection within the gynaecology clinic itself.

Following both Association of Social Anthropologists (ASA) and NHS guidelines, both patients and clinicians were given a consent form which emphasized that all information given to the researchers would be kept confidential. The consent form stated that nothing patients said, either positively or negatively, would influence their clinical care. In addition, all subjects were provided with information sheets explaining the study (See Appendices). All subjects were supposed to be given at least 24 hours to decide whether or not to take part in the study. However, it was not practically feasible to be in contact with patients 24 hours in advance of their visit, and medical charts were accessible for me to review only on the day of the clinic. However, in light of these practical hurdles, I redoubled my efforts to explain the study to the subjects and to check at several points that they understood what I was saying. All patients provided a verbal consent for me to be present in the examination room and subsequently signed the consent form at the time of the visit. All patients were provided an information sheet that included my phone number and email address to be used if they had concerns and wanted to withdraw.

Subject anonymity was maintained throughout with all subjects being only referred to by initials and the audio-recording only listened to by the researcher. Within the thesis, all names of research participants have been changed to pseudonyms. The computer used for storing the recordings, for producing transcripts, and for replaying the recordings was password protected. Any print-outs were kept in a locked box and shredded when no longer needed. Data were to be stored for up to three years to allow time for completion of the dissertation.

While there was little risk of any harm to subjects involved in this study, the nature of endometriosis and chronic pelvic pain is such that many topics may be considered sensitive. Endometriosis is associated with menstruation, pain during sex, infertility,

possible hysterectomy with the associated potential loss of the ability to have children. These are topics often considered sensitive or embarrassing in our culture and therefore potentially upsetting to the participants of the study. Any participants feeling upset were to be referred to their GP for appropriate help. During the course of my study, many patients did cry during the interviews, but generally patients left expressing happiness that they were finally able to speak of their experiences.

The topic of what is considered a good or bad doctor-patient encounter risked bringing up feelings of resentment, or generally upsetting the interviewee. This may also have touched on feelings of failure on the part of both clinicians and patients involved. Doctors may have feared reprisals on the part of the NHS if they felt that things had not gone well with patients. The study did risk worsening the interaction between specific doctors and patients.

Doctors and nurses in the gynaecology clinic seemed for the most part unaware that they were also considered subjects of this research. For many, their inclusion as participants was unknown, and therefore the research was, to a certain extent, covert. However I did not intend for the research to be covert in any way. All medical professionals were told multiple times of their role as study participants. This may have something to do with a misunderstanding of participant observation as a method of data collection. It may be that only interviews were considered a method of data collection. Those medical professionals I did not interview for the most part did not consider themselves to be study participants despite my repeating this whenever I saw them. They were told when I first met them, again every morning or afternoon, and a third time when I might be directly observing them in their clinic room.

It may be that the medical professionals considered patients more suitable study subjects than themselves. It may have been related to how the physicians saw the role of being study subjects: perhaps it was a form of submission to the researcher, who had the upper hand in the research activity. Introduction of the researcher's presence into

the clinic may well have changed the power structure in the clinic. Those few medical professionals who were aware of their status as study participants generally understood my research to be an evaluation of their work. This interpretation of the research objectives may have had an impact on their behaviour.

Much of my fieldwork in the hospital involved sitting at a nurses' station where I overheard some discussions on patient care. Within the hospital, it is almost impossible to not overhear discussions on patient care if you are sitting in a nurses' station. These discussions were, however, anonymised – in this case with the use of 'she'/'her' pronouns, with the use of names very rarely pronounced. Thus, I would never have been able to link a name with medical information without prior consent from the patient herself. In my fieldnotes, I avoided identifiable information on patients to further maintain any anonymity. I also did not include in my fieldnotes any data on patients who did not have endometriosis, chronic pelvic pain, or dysmenorrhoea. Though I never wrote down notes about patient care that appeared unrelated to endometriosis, I could not help but overhear some discussions.

While I had approval to listen to medical discussions around patient care for those patients involved in my study, separating out those discussions I was 'allowed' to be privy to and those I technically should not have overheard was difficult. I did not take notes on specifics of medical care on women who were not included in my study, nor did I include such data in this thesis. I did, however, include general themes when they appeared related to women with endometriosis. Of course, this ethics tightrope was difficult to negotiate, especially as the medical professionals involved felt that I was essentially one of the team and therefore privy to hear all conversations related to general patient care. This related often to notions around confidentiality in medical ethics where it is accepted practice to speak about patients in public provided no identifying characteristics are involved that would allow specific patients to be identified. As they did not use names, or dates of birth, it would have been difficult for me to associate discussions with specific patients. I was also not allowed to read through patient files before agreement from the specific woman in question, as

stipulated in my NHS ethics forms.

It could be argued that I could have waited in another place for patients who might be included in my study, but owing to the size of the clinic this would have required staying in another part of the hospital. Because busy healthcare professional were not able to come get me when they had a patient who fit the criteria, I would not have been able to carry out the research. Another solution could have been to conduct such research in a clinic reserved exclusively for endometriosis patients. This would have been difficult, as in this particular hospital such a clinic did not exist.

This is, of course, a by-product of conducting fieldwork in a medical establishment that was not solely an endometriosis clinic. Thus, there were some patients who did not fit my study criteria. Having said that, it is because of this reality that I was able to uncover such rich ethnographic data on the a-diagnostic category and the unclear boundaries of endometriosis as a diagnosis. This may not have become apparent if what was defined as endometriosis had been pre-determined.

The ethics of using online posts is a hotly debated issue related to the internet. Information posted online is considered to be within the public sphere, especially in the case of open-access forums as is the case here. Therefore, its use in research, although justified, evokes the notion that people using online forums may not be looking for public visibility and thus may not have given their consent for the information to be used. This unresolved debate appears to parallel issues around covert versus overt research in ethnography (Convery and Cox 2012).

VI. Access/Gatekeepers to Various Groups

Gaining access to my field of study and my participants was complicated. Interestingly, it was more difficult to access medical professionals than patient informants. Comments by Bryman (2004) relating to the distinction between overt (announced as research to the participants) and covert (hidden, unknown) research are of particular

relevance to this study. While officially my research was overt from the point of view of the NHS, it can be argued that it was at the same time covert. Members of the clinic were aware of research related to endometriosis patients but did not link the idea that they too were participants in this study, despite being told repeatedly.

Access to research participants was, on occasion, made more difficult by gatekeepers encountered in various settings of research. Gatekeepers have been defined as 'the sponsors, officials and significant others who have the power to grant or block access to and within a setting' (Walsh 2004: 229). He suggested that:

> …whoever the gatekeepers are, they will be concerned with the picture of their community, subculture, group or organization and may want it and themselves painted in a favourable light. This, in turn, means they are likely to keep sensitive things hidden. They may also prevent the study of mundane matters because they take them for granted and see them as uninteresting (Walsh 2004: 231).

Therefore, 'Access affects the accuracy of ethnographic study because it determines how and where fieldwork can be organized' (Walsh 2004: 231).

It can be argued that agents employed by the NHS became gatekeepers to my research occurring in the gynaecology clinic. During the ethics review, the questions raised seemed focused on the potential for the organisation to be put under scrutiny. The NHS needed to be reassured that it would be protected from any potential negative fallout. The clinic provided two major gatekeepers. The first was the consultant who, after many discussions, welcomed me into his clinic. The second was the head nurse who facilitated or stopped me from seeing certain patients. It was she who in many cases determined which patients were suitable for my study. She easily included patients on the basis of a pre-existing diagnosis of endometriosis in the file, but struggled with patients who did not yet have a diagnosis. This reflects enactments of endometriosis in the clinic, something I cover in detail in Chapter 5.

I did not observe any changes in whom the head nurse deemed suitable for my study as I became more trusted in the clinic. This may have been because I was largely trusted as an insider, medically speaking. As time went on, I was given more flexibility to

decide who was suitable. So, while her decisions remained the same, I was able to override her decisions as long as I acknowledged her comments regarding the suitability of the patient. Eventually, I read through patient files to determine if patients were eligible.

Such gatekeeping may of course have limited my ability to recruit 'difficult patients' through the gynaecology clinic. The question then was whether I was able redress this potential imbalance through recruitment from the support group. Certainly, the consultant gynaecologist who first allowed me access to the clinic would think so. His main reason for allowing me access to the clinic in the first place was because he strongly believed that support groups were filled with only the most difficult of patients, the ones who don't get better and the ones who have many complaints. He was afraid that I would get a negatively skewed picture if I only included 'difficult patients', which for him were those who have links to support groups. This notion, ironically, allowed me access to the gynaecology clinic.

Did I have contact with more 'difficult patients' by accessing the support groups? This is a difficult question to answer. The term 'difficult patient' refers to the patient or to the notion that the case is complicated and remains unclear (Maatz et al 2016). It was hard to define the 'difficult patient', as the women themselves did not describe themselves that way. This very issue is at the heart of this work. As I discuss in Chapters 5 and 6, the 'difficult patient' often is the one who finds herself in the a-diagnostic category, ultimately losing the endometriosis label.

Regarding the patient support groups, the heads of the local support group first introduced me to the group and ultimately allowed me to conduct my research. I did send a letter of introduction to the support group leaders by email and was then invited to attend one of their meetings to introduce my study. From there on, I was welcomed with open arms. While this may have been the result of my being considered a fellow endometriosis sufferer, I do believe that the members of the support group also felt it very important to fight for the 'endometriosis cause' in every way possible.

As far as access to specific health professionals in the gynaecology clinic, this was largely facilitated by my status as a fellow medical professional (doctor), with Mr. Xavier making introductions either in person or through email. My introduction to the pain clinic came about after I attended a lecture given by the head of the pain clinic, a pain consultant. I made an appointment with him to explain the project and then to interview him. After this, he facilitated further introductions, and a presentation to the clinic about my project.

VII. Methodological Limitations

Overall, a limitation to this study was the difficulty in recruiting health professionals and women with endometriosis. Arranging for semi-structured interviews with women recruited from the clinic was sometimes difficult because they were often unable to make the time or travel far. It is also possible that my results here could have been skewed to a specific subset of patients and medical professionals. Indeed, health professionals agreeing to semi-structured interviews may have had an interest in endometriosis and its effect on patients. Women in the study may have had bad experiences of both endometriosis and/or medical professionals. They also seemed to see endometriosis as a cause that demanded their support and that others needed to hear about.

A. Semi-Structured Interviews

Semi-structured interviews have been considered 'active interviews' in which the interviewer and interviewee are considered as equal partners in constructing meaning around the interview. The interviewer is said to "activate narrative production" (Holstein and Gubrium 1995: 39) allowing for an interviewee's story to unfold. However, because the interviewer still maintains control over the direction of the narrative, her position of neutral inquiry may be compromised (Holstein and Gubrium 1995, Fontana and Frey 2005).

The success of semi-structured interviews may depend in large part on the questions asked as well as on the quality of the interaction between interviewer and interviewee. In addition, as the goal of the interviews is to elicit a narrative surrounding endometriosis, it is possible that the subject may veer from the core topic (Flick 2002). I did not experience this during my interviews, with the exception of a focus on gendered understandings of endometriosis that women brought up and that I ultimately included in subsequent interviews. Audio-recording may have an impact on what is said within the interview. It may be that the subjects were reluctant to address certain topics knowing that a permanent record was being created (Rapley 2004). This was notable in interactions with consultant gynaecologists with whom I conducted both semi-structured interviews and informal interviews. Here they discussed remarkably different topics based on what they felt was 'officially' documented.

B. Questionnaires

The benefits of this method were ease of both time and location. As the participants from the national support group were scattered across the UK, it would have been difficult for me both time-wise and financially to interview them in person. Thus, sending the questions through email appeared a more feasible solution. Disadvantages of self-administration include the necessity of a good internet connection, ease of internet use, as well as good reading and writing skills by the participants. I was not there to help guide or answer any questions, and of course it was difficult to know for certain who it was that answered the questionnaire (Fowler 2009) and how they may have interpreted individual questions.

C. Informal Interviews

These have been previously 'characterized by a total lack of structure or control' (Bernard 2006: 211). In informal interviews, '[t]he researcher tries to remember conversations heard during the course of a day in the field' (Bernard 2006: 211). Therefore, drawbacks are that data may not be correctly noted and remembered as these conversations were not audio-recorded. However, informants may have felt freer to

speak about sensitive topics such as sexual intimacy, rape, feelings of inadequacy, and feelings of anger towards patients as was seen in interactions with consultant gynaecologists, for example. In addition, informal interviews did not have a set list of questions. They were spontaneous and were likely to represent what the interviewee deemed important.

D. Participant Observation

The collection of data through participant observation is an "inherently subjective" exercise (Delamont 2004). The observations made by the researcher are influenced by her own cultural history and are therefore dependent on previous ideas about her subject and her topic (Bailey 1996). Furthermore, participant observation during a consultation may interfere with the true interaction between doctor and patient and may skew it somehow. The presence of the researcher may also limit what the participant feels she can reveal regarding certain issues, such as sexual matters.

E. Visual and Textual Analysis

Both visual and textual data were taken from online sources. While the source of the data does not intrinsically alter the method of data analysis, its provenance remains relevant. It has been suggested that online support groups provide a level of anonymity that face-to-face contact cannot, thus allowing for greater discussion of stigmatized issues such as endometriosis (Baym 1998). Online support groups may offer greater interaction amongst people who are neither in the same place, nor perhaps even online at similar times (Baym 1998), possibly allowing women who are very ill to communicate with others without leaving their homes.

VIII. My Positionality as Researcher

I have the unique position of being both a medical doctor and an endometriosis sufferer. I have therefore experienced both sides of the doctor-endometriosis patient interaction. While this most certainly affected my interpretation of the data, it also allowed me to interact freely and access my participants, as both groups felt I could be trusted. I do

believe I was given more and different information because of my perceived status as a member of both groups. Both patients and medical professionals saw me as one of their own. Thus, potential matters of power imbalance between researcher and participant, especially during an interview encounter, were perhaps limited. While such power imbalances in interviewing have been documented by many (Ribbens 1989, Oakley 1981, Custa-Briand et al 2015), and it is debated as to the inevitability of such a power differential (Hammersly and Atkinson 1993), I suggest here that having commonalities with the participants decreased the power differential. This parallels Custa-Briand et al (2015) who suggested that specifically disclosing the status of the researcher as a 'non-health professional' decreased the power imbalance with patients involved in the research. Being in both groups of participants meant that I achieved 'trust' more quickly, as it was assumed that my 'goal' in doing the research was the same as theirs. While also true of the medical professionals I interviewed, this was especially the case with patients who, upon identifying me as having experienced similar struggles, felt that we were after a common goal of highlighting issues of access to care and the associated feeling of being dismissed by medical professionals.

This fostered high levels of trust amongst all participants, especially patients recruited from support group meetings. While this is generally a positive attribute in research, I point out that patients may have assumed a high level of shared goals in the research. They opened up to me more as a result, and felt comfortable in sharing sometimes quite shocking examples of negative experiences with the health system.

Medical professionals felt comfortable recounting their negative experiences with endometriosis patients and their struggles treating the disease. However, their view of my positionality as physician-researcher, not patient-researcher, or simply researcher meant that medical professionals expected a certain level of comprehension of 'medical speak', and often communicated an expectation of prior knowledge and that our viewpoints on specific issues would coincide. It also meant that health professionals often began statements such as '*well you know*' implying that it was a confidence that they would perhaps not have shared with someone they considered to be

an outsider.

Depending on this, within the clinic, patients were introduced to me as either a doctor doing research on endometriosis or Véronique. Sometimes there was no formal introduction. Some patients, when only introduced to me by name, assumed that I was a student or an NHS gynaecologist conducting research. Therefore, patients in the clinic were often unclear as to my precise position and role within the clinic, a likely by-product of doctors' within the clinic often conflating my role as researcher and what they viewed as the role of a fellow doctor (albeit one not participating in clinical activities).

While the women who met me in the clinic were happy to participate in the study, provided they had the time, my introduction impacted what they would have said. This was particularly obvious with the one woman to whom I did not first explain that I had endometriosis. The beginning of the interaction was quite formal, and I felt she was unsure of what she could say without potentially affecting her ability to access treatment (despite being expressly told by both her consultant and me that participation would not influence her care in any way). It was only after about five minutes that I took the time to explain my status as fellow sufferer, and then she began to open up more readily.

My access to the NHS clinic itself was based largely on my status as 'fellow medical professional'. It was only through the consultant's acceptance of me and my project in his clinic that I was able to do research in the NHS. He was therefore responsible for introducing me to his co-workers, at least at the beginning of my fieldwork in the clinic. Medical professionals took to the notion that I was a medical doctor, and therefore 'one of them', largely due to my introduction to the clinic staff by the consultant gynaecologist.

As a trained physician, I have the eye of a clinical person who can observe the

happenings in a clinical setting without much explanation. Observations of structure and process in the clinic and its medical work may be easier for me to pick up than someone who does not have medical training. Of course, this also meant that certain elements of the runnings of a hospital clinic may appear 'normal' to me such that I may not have thought to comment on them. I may also have my own preferences for how the clinic ought to be organized, for example.

My status as a woman with endometriosis meant that some women saw me as someone with experiences similar to theirs. They felt I understood easily their experience of endometriosis and of seeking medical care. While in some cases this was true, at that time I had most of my experiences with US medical care and little knowledge of endometriosis care in the NHS.

As a fellow patient, I may have the tendency to identify with someone who also suffers from endometriosis, causing me to be overly sympathetic to certain struggles or experiences with the disease. This may also allow for increased sensitivity especially around topics linked to stigma, such as pain during sex or infertility and more thoughtful assessment and evaluation.

IX. Conclusion

This chapter has examined the methods used in this ethnographic study of endometriosis. I described the research participants as well as the specific methods employed such as semi-structured and informal interviews, participant observation in various contexts, textual analysis of data and visual analysis of online representations of endometriosis. I also discussed ethics and the potential methodological limitations to this research. There is an historical dimension to the multiplicity of endometriosis, which it is important to elucidate. This will be the subject of the next chapter.

CHAPTER 3

Historical Notions of Menstruation and the Diagnostic Category of Endometriosis

I. Introduction

I now turn to a history of menstruation and the emergence of endometriosis as a diagnostic category. This history will allow us to frame the fight of women with endometriosis against the psychologisation of endometriosis (and the link to the a-diagnostic category) and their ultimate struggle for a unitary label of endometriosis. I argue that the historical notions about women's bodies and menstruation continue to affect the present-day diagnostic category of endometriosis.

I consider how the notion of women as innately ill has been perpetuated throughout the centuries, specifically in relation to menstruation and the associated uterus. I draw on an historical analysis and chronological account of menstrual pain as well as contemporary biomedical constructions of endometriosis to argue that women's bodies were and remain 'unruly' and in need of management and control. The uterus is seen as both symbolic of women's bodies as a whole and in some cases seen as separate, needing to be 'tamed' (Martin 1987), either by pregnancy or by the maintaining of women's roles in society. The historical record underlines how social understandings of women's roles in society impacts notions of women's bodies and their pathologies, such that painful menstruation was and is considered normal. Such conceptualisations of the uterus as being in need of control, of menstruation defined as painful, and pregnancy as the potential cure for all, have remained embedded in the relatively new diagnostic category of endometriosis which first appeared in the 1920s.

These ideas about gendered cultural conceptions of women's roles impacting on notions of women's bodies parallel Emily Martin's description of how metaphors of economic production are incorporated into understandings of women's reproductive health (Martin 1987). However, Martin (1987) did not address the persistence into the present day of ideas of women's bodies stemming from as long ago as the Ancient Greeks. Based on interviews and fieldwork done in the United States in the 1980s, Martin (1987) argued that women's menstruation was seen as negative. It highlighted their lack of production (of children). Similarly, women's one egg, compared to men's many

sperm, also highlighted women's lack of production, which left women's bodies negatively valued compared to men's bodies. Metaphors of women's reproductive health continue to be influenced by cultural and economic understandings of women's place in society, with women being expected to produce children (Martin 1987, Martin 1991). Women's roles thus may influence cultural understandings of women's bodies and how they are described. This is particularly important with regards to perceptions of menstruation, which incorporate cultural understandings of women's roles that have not changed much in many centuries. These past social understandings remain implicit in the diagnostic label of endometriosis. Thus, while metaphors of women's health and specifically menstruation remain linked to the cultural roles of women (Martin 1987), historical concepts of menstruation still affect the present-day diagnostic category of endometriosis.

Previous histories of endometriosis (Batt 2011; Benagiano and Brosens 1991, 2011; Benagiano et al 2014; Knapp 1999; Nezhat et al 2012; Redwine 2012) have suggested that symptoms consistent with what is now termed endometriosis have been described since the ancient Egyptians ca. 1825 BC. The term endometriosis itself was not used until 1925 by John A. Sampson M.D. of Troy, New York, USA (Dastur and Tank 2010, Clement 2001, Benagiano et al 2014, Sampson 1927).

The history of endometriosis is complicated by questions about the link between hysteria and endometriosis. Several authors (Redwine (2012), Nezhat et al (2012)) have directly linked hysteria to endometriosis, with Nezhat et al (2012), for example, suggesting that any reference to hysteria can also be endometriosis. However, this link is tenuous, as hysteria was never a stable diagnostic category. Sources have connected hysteria to convulsion or epilepsy (Arnaud 2015, Didi-Huberman 2004), with these texts generally discussing Charcot's understanding of hysteria, or relating it to mental illness or neuroses (Freud and Breuer 2004, Veith 1965, Micale 1995). These texts were all linked in some way to Freud, to gynaecological illnesses including endometriosis (Nezhat et al 2012, Redwine 2012), or to a vast array of other behaviours and physical symptoms (Showalter 1997, Bogousslavsky 2014). Hysteria has been applied broadly:

from limps to paralysis, seizures, cough, headache, and speech disturbances, all associated with the woman's body (Showalter 1997). Definitions of hysteria remained varied and non-specific, and described different afflictions. In 1561 for example, hysteria was defined as 'suffocation of the womb', while in 1667 hysteria was linked to convulsions (and what we now think of as epilepsy) by Thomas Willis (Arnaud 2015). Debates abound about hysteria and which diseases affecting women the term referred to, with the only consensus appearing to be hysteria's link to women's bodies and to the uterus.

Ultimately, this non-specificity of the term hysteria is likely related to the origin of the term, with hyster meaning 'uterus' in Greek, and thus the condition being first and foremost linked to the uterus (and therefore indirectly to women) (Arnaud 2015). As I describe further in this chapter, the 'wandering uterus' was associated for centuries with most forms of ill-health in women, both physical and mental. As hysteria was simply seen as a manifestation of an illness related in some way to the uterus (hyster) and ultimately to the 'wandering womb', any symptoms could be caused by hysteria. This association between the uterus and gendered understandings of physical and mental health highlights the contested nature of the diagnostic category endometriosis, with menstrual pain still considered 'normal' and complaints about menstrual pain symbolic of mental illness, such that women with endometriosis still report being given alternative diagnoses of depression or simply being told it is 'all in their head'.

Although endometriosis is a relatively new biomedical category, there is a substantial historical record that mentions pain during menstruation, a major symptom of endometriosis, including texts about dysmenorrhoea and 'normal' menstruation (as 'normal' menstruation was considered to be by definition painful). [2] In this section, I analyse how these symptoms have appeared and been described in the historical record, drawing particular attention to the longevity of the notion that 'normal' menstruation

[2] I have found different articles on the history of menstruation, dysmenorrhoea and endometriosis all use the same examples to support their differing claims (Rehman et al 2013, Sultana et al 2015, Redwine 2012, Nehzat et al 2012).

was seen as intrinsically painful. This notion stems from social understandings relating the role of menstruation and the uterus to women's duty to produce children, an association that remains current. Thus, it is difficult to separate endometriosis from several diagnoses, which include dysmenorrhoea and depression, a situation that reflects the current social understandings of menstruation. Such gendered notions continue to the present and ultimately influence the understanding of endometriosis as a diagnostic category with its associated controversies.

II. Women as Innately Ill

A. The 'Wandering Uterus'

In 1825 BC, in the Kahun Medical Papyrus, thought to be one of the oldest medical texts in existence, we first find the link of the uterus to ill health in women (Dixon 1995). This appears to be the earliest mention of the notion of the 'wandering uterus', an idea that the womb can move around at will and that movement away from its natural place in the pelvis causes ill health in women. At the time, any illness in women was considered related to the 'wandering uterus' (Dixon 1995). For example, aching eyes and necks were seen to be 'discharges of the womb', and aching teeth were described as a 'toothache of the womb' (Kahun Papyrus 1825 BC: Column 1, 15-20). A woman with pain in 'her rear, her front, and the calves of her thighs' had 'discharges of the womb' (Kahun Papyrus 1825 BC: Column 1, 8-12). This notion of the 'wandering uterus' is seen again in a later Egyptian text, the Ebers Papyrus (ca. 1550 BC) which also 'recommends cures designed to lure the uterus back into the abdomen' (Dixon 1995: 16). Thus, women were dominated by their uteri, with the misbehaviour of the womb the cause of all illnesses. This 'unruly' behaviour on the part of the uterus paralleled the ultimate misbehaviour of the woman herself who needed to follow the womb in its ultimate role as producer of children or risk the wandering of the uterus with its many associated illnesses.

B. The Hippocratic Corpus

Later texts of the Greek period continued the association between menstruation and ill health. The Hippocratic corpus, a series of medical texts from the 4th and 5th century BC written by various writers called the 'Hippocratics', presented humoral medicine whose tenets were linked to the concept that four elements (cold, heat, dryness and moisture) made up the body. Each person was thought to have a constitution of humours that, if maintained in balance, allowed one to remain healthy. If the humours became unbalanced, illness occurred. Diseases were not separated into distinct clinical entities, as it was thought that symptoms could be connected one to the other depending on how the humours behaved (Eccles 1982).

Men were considered to be 'hotter' than women, with heat being linked to strength, vigour, courage, and intelligence. As women were colder, they were also lacking in the above qualities, making them both inferior to men and less healthy. Women who did not menstruate were naturally hotter than other women and were considered healthier than women who had periods. Women were considered intrinsically 'ill'. This concept persisted for many centuries (Eccles 1982) with menstruation considered a state of normal abnormality with associated pain. This notion that 'normal' menstruation is painful remains a barrier to accessing care for endometriosis (Denny and Mann 2008, Markovic et al 2008, Manderson et al 2008) and is a topic we will return to later.

Like the Ancient Egyptians, the Hippocratics, nearly 2000 years later, also believed the uterus to be mobile. They viewed the womb as an independent creature. It was thought to be one of the 'lower creatures of the earth' (Dixon 1995: 18), whose primary goal was reproduction. Again, there is this notion of the 'wandering uterus', a womb that had its own mind and moved at will. The uterus had to be controlled and returned to its rightful place. Without this, the uterus became responsible for the ailments that women experienced. Treatments that were suggested for most of the diseases of women were associated to the concept that the uterus had moved from its original position.

However, unlike the earlier Egyptian texts, Hippocratic theories suggested that menstruation was the only thing that allowed a woman to stay strong and healthy. It was a key process necessary to maintain the woman's bodily equilibrium. The idea that menstruation made a woman weak seems to have originated from Aristotle (Dean-Jones 1991). From this point onward, the notion that menstruation caused women to be weak has persisted, and has been used, as we shall see later, to justify the notion that women should stay at home and have children and not work or become educated.

The Hippocratics strongly felt that the cure to the 'wandering uterus' lay in marriage. For them, the uterus was meant to interact with 'male seed' and needed ultimately to fulfil its reproductive function. Thus, remaining a virgin was dangerous and unnatural (Dixon 1995). The uterus, as the living creature within women, had the single goal of bearing children. If it did not fulfil this role, the uterus would then wander and cause many of the illnesses women experienced. Plato, in his famous work *Timaeus*, explained that the womb:

> … is a living creature within [women] which longs to bear children. And if it is left unfertilized long beyond the normal time, it causes extreme unrest, strays about the body, blocks the channels of the breath and causes in consequence acute distress and disorders of all kinds (Plato 1971: 122-123).

The Hippocratics also felt that the displacement of the uterus was more common in

> … barren women, especially after hard work. When a woman works hard and her uterus heats up and sweats, her uterine mouth turns out through the vagina, since it was in a wetter, more slippery, and hotter place than previously. When this happens, the womb rushes toward the cold and its turned mouth moves toward the outside (Morb. Mul. 2.145 "C"= 8.320.2-7 in Hanson 1991: 83).

And intercourse and pregnancy were seen as cures for the 'wandering uterus' throughout the Hippocratic corpus.

> Intercourse and pregnancy not only prevented uterine displacement, through the moisture of the sperm and the ballasting provided by a baby, but frequently served as a cure (Hanson 1991: 84).

C. Mediaeval Gynaecology

The notion of the uterus as having its own mind and needing to be managed by proper fertility was perpetuated later in Mediaeval gynaecology, where Christian concepts became linked to medicine. Here, 'the troublesome uterus could be tamed by exorcism, consisting of prayer and physical chastisement' (Dixon 1995: 22).

A Latin prayer from the 10th century, looked to return the uterus to its rightful place.

> I conjure thee, O womb, in the name of the Holy Trinity, to come back to the place from which thou shouldst neither move nor turn away, without further molestation, and to return, without anger, to the place where the Lord has put thee originally (cited in Dixon 1995: 23).

The uterus was understood to be not only unruly but devil-like. And pain in the womb was linked to demonic possession. The dedication before the prayer cited above reads:

> To the pain in the womb. …. O womb, womb, womb, cylindrical womb, red womb, white womb, fleshy womb, bleeding womb, large womb, neufredic womb, bloated womb, O demonical one! (cited in Dixon 1995: 23).

D. The Renaissance to the 18th Century

During the Renaissance period (15th and 16th centuries), the Christian concept of using prayer to tame the uterus remained strong, with medical texts still visually representing the uterus as 'wandering' as seen in Figure 3.1 (Dixon 1995). However, Paracelsus, a vocal dissenter, rejected this idea that supernatural forces had any link to physical disease. Instead, he returned to the Hippocratic ideas linking mental and physical illnesses and explaining that uterine disorders 'caused irrational behaviour in women' (Dixon 1995: 40).

Throughout the 17th century, themes from Galen and the Hippocratics still abounded, as did notions of menstruation linked to the Bible, this time associated with menstrual stigma. Here again we see the concept that the uterus is responsible for many of the general illnesses women experience. For example, Queen Anne's doctor, Sir David Hamilton, suggested that she avoid being worried about state affairs to manage her symptoms of gout which as Crawford (1981) reminded us were still thought to be due to

the ‘wandering uterus’. We stay then with the notion of women in a natural state of ill-health.

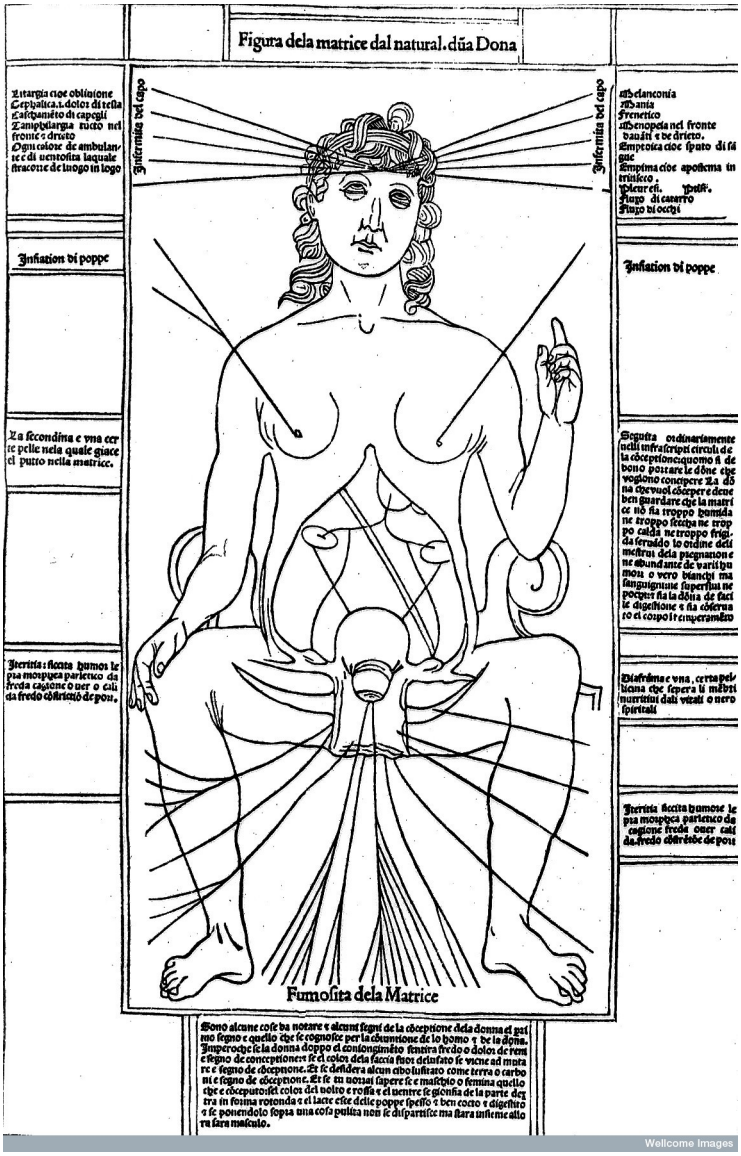


Figure 3.1
Depiction of the ‘wandering uterus’ from
The Fasciculo di medicina, Venice, Italy 1493.

The belief, that sexual intercourse and ultimately pregnancy would somehow solve problems with painful menstrual periods, lasted until the end of the 17th century, with John Pechey (1696) in his book *Diseases of Maids, Big-bellied Women, &c*., suggesting that:

> Some of these remedies were also applied to dysmenorrhoea, though far less attention was paid to this than to stoppage of the courses. Either painful

> menstruation was relatively rare, or seldom brought to the attention of medical men. Pechey pointed out that 'It is a Disease more incident to Maids than married Women, because the Veins of the Womb are less open in them, than in those who brought forth children. It happens sometimes that a corruption of the blood, that is from drossiness and thickness thereof, and then the blood clots together; and there is a great pain long before the Flowers begin to come down (Pechey 1696 in Eccles 1982: 76).

E. The 19th Century and Early 20th Century

In the late 1800s and early 1900s, the medical view persisted of 'women as innately sick' with menstruation or the absence of menstruation as abnormal and pathological (Ehrenreich and English 2011: 57). However, medical theory at the time focussed on the physiological law of 'conservation of energy' that postulated that a human body 'contained a set quantity of energy that was directed variously from one organ or function to another (Ehrenreich and English 2011: 64).

It was posited that energy could be diverted from one organ to another, with sexual organs (especially the uterus) competing with other organs for this energy. As reproduction was a vital role for women at that time, energy was to be focussed on the womb and not used for 'unwomanly' pursuits such as intellectual learning. The pathologizing of menstruation was therefore used to justify notions of 'female invalidism'. Women needed to stay home while having their periods, and, they should not be admitted to medical school, attend higher education and vote (Ehrenreich and English 2011). For example, in a text published in 1871 Dr W.C. Taylor wrote:

> We cannot too emphatically urge the importance of regarding these monthly returns as periods of ill health, as days when ordinary occupations are to be suspended or modified… Long walks, dancing, shopping, riding and parties should be avoided at this time of the month invariably and under all circumstances. … Another reason why every woman should look upon herself as an invalid once a month, is that the monthly flow aggravates any existing affection of the womb and readily rekindles the expiring flames of disease (Taylor 1871 cited in Ehrenreich and English 2011: 55).

Once a month, due to menstruation, a woman became an invalid.

In 1874, Dr Edward H. Clarke wrote his famous book *Sex in Education; or a Fair Chance for the Girls* with a second edition published in 1875. He espoused the theory that women's education risked making them grievously ill. The suggestion was ultimately that women should either not be educated or at the very least be educated separately with different information suitable for women. He explained that women were not inferior to men but simply different and should be treated differently because physiologically they could not handle men's work any more than men could handle women's work. He suggested women should not be educated as men, but rather as women.

> Wherein they are men, they should be educated as men; wherein they are women, they should be educated as women. The physiological motto is, Educate a man for manhood, a woman for womanhood, both for humanity. In this lies the hope of the race (Clarke 1875: 19).

Clarke saw education as not only book-related but also as connected to the role of women more generally, with an implication that women were to stick to their defined roles. Any education outside of expected norms such as motherhood, constituted being educated as men. He explained that:

> Education is not used in the limited and technical sense of intellectual or mental training alone. … Education is here intended to include what its etymology indicates, the drawing out and development of every part of the system; and 'this necessarily includes the whole manner of life, physical and psychical, during the educational period' (Clarke 1875: 20).

Clarke's book espoused the notion of 'conservation of energy' this time from the uterus (through menstruation) to the brain. Too much activity in the brain would cause ill health. '[T]he educational methods of our schools and colleges for girls are, to a large extent, the cause of "the thousand ills" that beset American women' (Clarke 1875: 22).

He directly linked illnesses such as amenorrhoea, dysmenorrhoea, and chronic and acute ovaritis to what he called 'a neglect of the peculiarities of a woman's organization' (Clarke 1875: 23). He went on to explain that if the gynaecological organs of a woman were properly cared for and not neglected through use of her energy in education, they would allow her to remain healthy.

> If properly nurtured and cared for, they are a source of strength and power to her. If neglected and mismanaged, they retaliate upon their possessor with weakness and disease, as well of the mind as of the body (Clarke 1875: 33).

Clarke's book was reputed to have created much debate (Clarke 1875). A review of the first edition from 1874 presented concern that the text could be used as a reason to bar women from education. It suggested that while the potential harm of women's 'excessive brain-work' (The North American Review 1874: 141-142) was well founded, women still needed to be educated to 'adapt themselves for what is demanded of them by men who seek to make companions of their wives' (The North American Review 1874: 142). The review recommended that women be educated, but to prevent excessive brain use, this education should be supervised.

> …if properly supervised, that excess may be avoided, gives occupation to the mind at the time of its unfolding, when she ceases to take interest in childish things, and when, if worthy objects do not claim her attention, she is likely to devote it to things unworthy (North American Review 1874: 143).

Although Clarke's book provoked considerable discussion, the views that it was normal for menstruation to be painful and that menstruation generally affected women's health were commonly held. In 1916, Dr Winfield Scott Hall wrote:

> All heavy exercise should be omitted during the menstrual week … a girl should not only retire earlier at this time, but ought to stay out of school from one to three days as the case may be, resting the mind and taking extra hours of rest and sleep (Hall 1916, in Ehrenreich and English 1978:111).

III. Women as Mentally Ill

In the late 19th century, another debate began. Menstruation was considered a 'normal' physiological process, despite its association with pain. At the same time, a link was established between menstruation and 'mental' ill-health echoing the shift in thinking concerning hysteria as a psychological condition. Two schools put forward the psychologisation of hysteria: the school of Nancy, France where Hippolyte Bernheim 'interpreted hysteria as an exaggerated psychological reaction' (Micale 1995: 26); and the school from la Salpetrière in Paris, where several researchers including Freud began

to question the notion of causality in hysteria. The latter claimed that hysteria 'was a psychological disease with quasi-physical symptoms', a reversal from previous understandings where the physical was seen to cause psychological symptoms (Micale 1995).

Robert Bell, M.D., physician to the Glasgow Institution for Diseases of Women and Children, gave a presentation about dysmenorrhoea at the very first meeting of the British Gynaecological Association in 1885. He wrote that:

> We cannot, of course, designate the periodic engorgement of the uterine tissue as disease, when it completely disappears with the cessation of the activity in the ovary, any more than we can call the condition of the stomachic mucous membrane which induces the sensation of hunger, congestion (Bell 1885: 55).

A. The Early 20th Century

By the early 1920s, there was a need to replace men in the workplace because of losses during the First World War, and menstruation could no longer be regarded as an impediment to women's entrance to the workplace (Strange 2001). At this point, and despite much opposition, some female doctors began asserting their influence through articles and medical presentations with the goal of shifting view-points about menstruation (Ehrenreich and English 1978, Strange 2001). For example, in 1920, Alice E. Sanderson Clow, MD, wrote in the British Medical Journal:

> To every girl I explain that menstruation is not a malady but a natural function, and that the natural function and proper thing is for her to feel quite well and free from pain and any other unpleasant sensations. I emphasize that it should not be necessary to lie down, and that if she feels too poorly to enter into the ordinary life of the school, she should have advice from her doctor as any trouble connected with her period can be much more easily put right now than after it has become established for years.
>
> I further explain, usually to her great astonishment, that it is quite safe for her to have a bath.
> …
> With regards to exercise, I tell her that, provided she feels well, exercise will do good rather than harm, and that there is no need to cut herself off from walking, cycling, horse-riding, outdoor games, dancing or gymnastics. Swimming, for obvious reasons, cannot be indulged in. I furthermore explain that most

> unpleasant sensations associated with menstruation are dispelled by a brisk walk, whereas they are prolonged by lying down (Clow 1920: 512).

In response, Mary Andrews MRCS felt that Dr Clow failed to consider the negative consequences of too much activity during menstruation. She explained that Clow did not fully consider the 'possible dangers which may occur in later life due to over-activity in the periods during school or early life' (Andrews 1920: 568).

She illustrated her point with the following example:

> An athletic country girl passed through her schooldays and holidays without a single day of menstrual pain and never gave up any game, however strenuous, at such times. She afterwards played a great deal of cricket, hockey and tennis; rode and took very long walks. She laughed at those who rested. At the age of 21 she entered college life as a medical student, of dragging pain during the period, which made the long laboratory hours difficult at those times. However, she never laid up, and being a day student had ample exercise, usually walking about five miles a day. The last few years she has been practically incapacitated for forty-eight hours during each period, and is too weak often to walk half a mile. The least over-exertion brings on a large flooding, even after the period has apparently ceased. She now greatly regrets the folly of her former strenuous exercise at those times (Andrews 1920: 568).

Despite these dissenting voices, Clow aimed for a clear distinction between 'normal' menstruation and dysmenorrhoea. In a 1924 meeting of the British Medical Association in Bradford, she wrote:

> Dysmenorrhoea is a word to which so many definitions have been given that it is necessary to state in what sense one is using the term. This entails an understanding as to what we mean by 'normal menstruation.' Experience has taught me that menstruation is a function which, when normal, has no symptoms. If there were not external evidence of it a large proportion of women would not know when it was taking place. This is the normal state of affairs. Suffering of any kind associated with the menstrual period is abnormal and included in the meaning of the word 'dysmenorrhoea' as used in this paper (Clow 1924: 558).

In response to Clow's 1924 article, Aleck Bourne from London explained that there were two classes of dysmenorrhoea:

> first, the large class of artificial menstrual invalids, the result of the teaching of wrong ideas in adolescence; and secondly, the small group of real pathological

> dysmenorrhoea. The first group were difficult to treat, according to the age of the patient – difficult over 25 and almost hopeless over 30. The second group should be regarded from the pathological point of view, and treated according to requirements (Clow 1924: 565).

Here, we see the shift from menstruation physical ill-health to mental ill-health, where dysmenorrhoea is divided into two classes: 'artificial menstrual invalids', and 'real pathological dysmenorrhoea'.

The notion of normal menstruation as painless had a hard-time catching on. Instead, medical doctors started to consider the usefulness of decreasing fear and ignorance around menstruation as one that would helpfully 'reduce "psychoneurotic" disorders associated with periods' (Lead Article, 'Unwell', Lancet 16 June 1923, 1219-20, *in* Strange 2001: 260). By 1928, the *Lancet* began to question the significance and reliability of new research by female doctors noting that: 'both female practitioners and their subjects has a vested interest in proving that, as a sex, they were not periodically incapacitated' (Lead Article, Women's Work during the Menstrual Period', Lancet, 7 April 1928: 712, in Strange 2001: 260).

A 1930s pamphlet included in a copy of *Woman* magazine explained to mothers how to speak to their daughters about menstruation. This pamphlet urged a move away from any terminology of sickness and any personal examples of negative menstrual experiences (Strange 2001). Thus, there was a change in menstrual etiquette. Strange noted that it became 'a fixed definition of normative menstrual experience which devalued alternative concepts and expressions of menstruation' (Strange 2001: 262).

B. The 1960s

As recently as the 1960s, medical and hygiene publications continued to oppose recommendations that baths should be avoided during menstruation (Strange 2001). Menstruation remained 'dangerous' and 'perceptions of the menstruating body as disordered and out of control' still needed dispelling (Strange 2001: 260). At the same time, there was increasing discussion about the link between menstruation and the psychology of women. The shift from women as physically ill to 'mentally ill' became

more apparent. An article from 1964 entitled 'Menstruation and Personality' explained that previous articles had suggested that 'dysmenorrhoea is associated with certain personality types and is related to maladjustment or to resentment of the feminine role' (British Medical Journal 1964: 1000).

While dysmenorrhoea might be linked with a specific personality type, including women who 'resent the feminine role,' menstruation itself was associated with psychological changes, increased criminal activity, and acute psychiatric illness.

> That there are psychological changes [in menstruation] is not to be doubted; and they are associated with a higher accident rate, an increased incidence of suicide, of misbehaviour and criminal activity, and acute psychiatric illness (British Medical Journal 1964: 1000).

C. Since the 1970s

In 1979, the notion of menstruation remained still symbolically associated with pelvic pain. However, it was no longer acceptable for a woman to be an invalid during menstruation. Things had moved to a place where women who reported more difficulty with menstrual symptoms including pain were 'depressed' or 'irritable' or 'dissatisfied'.

> Well-adjusted, happy, and active women on the average seem to have less pre-menstrual difficulty than do those who are dissatisfied, bored, or depressed in general. Similar statements can be made for the severity of dysmenorrhea (Lein 1979: 95).

In the 1970s, a woman's expectations of how painful menstruation was determined her own behaviour towards her periods. Menstruation would not be a burden if she approached it in a positive way. The implication was that menstruation would only be painful if a woman did not fulfil the duty to accept her menstruation.

> It is believed by some that the severity of pre-menstrual and menstrual symptoms may, in part, be determined by how a young girl is prepared for her menstrual function. If she is told to expect 35 to 40 years of monthly misery and that menstruation is indeed a curse on women, if her mother is irritable and goes to bed for a few days each month, she may be more likely to experience menstrual difficulties. On the other hand, if the prepubertal girl is taught that menstrual cycles are simply a fact of life for women, if she knows the biological significance of the cycle, if she has been shown how to care for herself during a period and perhaps how her mother does it, then the probability is greater that her menstrual life will not be a burden (Lein 1979: 95-96).

Women remained intrinsically ill, but the social role of women had moved from 'physically sick' to 'mentally ill' (Ehrenreich and English 2011).

> [T]he tendency of doctors to diagnose our complaints as psychosomatic shows that the medical view of women has not really shifted from "sick" to "well"; it has shifted from "physically sick" to "mentally ill" (Ehrenreich and English 2011: 148).

The lack of a clear, organic cause of a woman's symptoms quickly led to a doctor's 'suspect[ing] psychosomatic causes' (Ehrenreich and English 2011: 147).

To a large extent we have yet to move past this focus on menstruation as a 'normal' state of abnormality or ill health. Symptoms of menstrual pain remain normalised and accepted in current day UK culture, ultimately contributing to the experience described by women with endometriosis of menstrual stigma and their common experiences of feeling not believed by their clinicians. The idea that 'it's a woman's lot to suffer' remains prevalent and affects time to diagnosis for women with endometriosis as well as their levels of emotional suffering.

IV. The Emergence of Endometriosis as a Diagnostic Category

The emergence of endometriosis as a diagnostic category in the 1920s was linked to a shift in medical culture. The change involved the new use of the microscope to visualize cells and an increase in abdominal and gynaecologic surgery resulting from the recent implementation of anaesthesia. In the eighteenth century, the microscope was linked primarily to popular culture and used for entertainment and as a toy. It was only in the 1830s that the first cell was visualised under a microscope (La Berge 1999). From the mid-nineteenth century onwards, the role of microscopy became more important, and the work of Bichat, Virchow, and Morgagni increased the prominence of pathology (Van de Tweel and Taylor 2010). At the same time, surgery advanced quickly after the implementation of anaesthesia in 1848 (Robinson and Toledo 2012). Surgeries for ovarian cysts began in the 1850s but remained rare due to the 50% risk of

fatality linked to infection produced when surgeons opened the abdomen (Gawande 2012). The combination of the ability to perform surgery and visualization of the disease under the microscope thus allowed for a shift in disease concepts from one of organs to one focused on cells (Van den Tweel and Taylor 2010). Advances in microscopy, surgery, and anaesthesia facilitated formulation of the diagnostic category of endometriosis, as now the abnormal cells could be seen. However, this simultaneously resulted in a separation between physical and visualised diseases, allowing past understandings of 'normal' pain in menstruation to remain despite the medicalization of medical pain.

While debates remain as to who first described endometriosis, and when, as the examples pre-date Sampson's first use of the term, all such descriptions of endometriosis are of visualised endometriosis. Some cite Carl Von Rokitanski, a Russian gynaecologist, as the first to describe endometriosis outside of the uterus (Batt 2011, Van der Linden 1996, Hudelist et al 2009), whereas others note that Von Rokitanski was in fact describing tumours either benign or malignant (Redwine 2012, Benangiano et al 2014). Knapp suggested that Von Rokitanski did describe endometriosis, but that he was not the first. Instead he attributed the first report of endometriosis to Schron in 1690 in his book entitled *Disputatio Inauguralis Medica de Ulceribus Ulceri* (Knapp 1999). Benangiano et al (2014) submitted that it was Thomas Cullen who first described endometriosis in 1896. In addition, Ivanoff claimed in 1898 that he was first to describe what he at the time had called an 'adenomyoma'. He stated that his report had not been acknowledged because it was published in Russian (Benagiano and Brosens 1991). All such descriptions of endometriosis remain linked to the visualisation of endometriosis through surgery.

Sampson, who was the first to employ the term 'endometriosis' in a 1925 publication (Sampson 1927), provided descriptions of the visual aspects of endometrial lesions as seen either microscopically or with the naked eye (cysts/endometriomas and adhesions). Sampson rarely spoke of patients' symptoms, only scattering rare case-studies throughout his 75-page article(s) (Sampson 1921). The focus was on the tissue, not the

woman herself or the symptoms resulting from the abnormal tissue, highlighting the beginnings of a biomedical orientation towards the disease that emphasized technological advancement (through the microscope) and involved one particular form of enactment of 'multiple' possible endometrioses (Mol 2002).

The creation of endometriosis as a new diagnostic category in the 1920s has much to do with the shift in medical culture and the emergence of a medical gaze as described by Foucault (1963) in his *Naissance de la Clinique*. Current medical definitions of endometriosis still emphasize the visualisation of endometriosis either grossly or through microscopy, with endometriosis characterized by the presence of endometrial-related tissue outside of the uterine cavity (Redwine 2004, Tulandi and Redwine 2004, Fritz 2005). Similarly, the only pathognomonic way to diagnose endometriosis remains through surgical visualization, most commonly laparoscopy (keyhole surgery). Magnetic Resonance Imaging, X-Ray, and ultrasound still do not have strong diagnostic accuracy for endometriosis (although they are methods of potentially visualising endometriosis).

Other than microscopy after surgical excision (cutting out) of tissue, other key diagnostic tools normally used in medicine such as physical examination with pelvic examinations remain unreliable for measuring the extent of the disease involvement (Practice Committee of ASRM 2006a, Practice Committee of ASRM 2006b). Physical examination may reveal tender nodules located in the posterior vaginal fornix, uterine motion tenderness, as well as tender adnexal masses. However, endometriosis patients may also present without showing any such signs on examination.

The differential diagnosis, or possible causes, of chronic pelvic pain is quite extensive. Therefore, it can be difficult to reach a diagnosis of endometriosis, further complicating endometriosis as a biomedical category. Differentiating among the many causes of pelvic pain remains complicated, especially as a good history and physical examination may not contribute meaningfully to clarification of the diagnosis (Practice Committee of ASRM 2006a, Practice Committee of ASRM 2006b). Ultimately, the gold standard

for diagnosis of endometriosis from a biomedical viewpoint clearly remains tied to visualisation of endometrial implants. However, the link between visualised endometriosis and symptoms remains unclear, and often there is no direct correlation between the number of endometriosis implants and severity of pain.

A major deficit in biomedical knowledge of endometriosis is that the cause of endometriosis remains unknown. Sampson, who published 18 articles as a sole author, remains a key source on terminology and theories of endometriosis. His ideas still permeate clinical discourse on endometriosis (Clement 2001). Sampson suggested several major theories regarding the cause or pathogenesis of endometriosis which still remain in use to this day. Four main theories of causation have been put forward. The first, the Retrograde Menstruation Theory, states that backwards menstrual flow through the fallopian tubes allows for endometrial tissue to be deposited in the abdominal cavity (Fritz 2005). However, retrograde menstruation has been said to be a common phenomenon found in up to 90% of women, suggesting that there are other factors involved in the formation of ectopic implants (Gazvani et al 2002, Crosignani et al 2006) such as molecular and immunologic abnormalities (Bulun 2009).

The second theory, the Lymphovascular Metastasis Theory, states that endometrial cells are distributed through both lymphatic and haematogenous spread, where endometrial cells pass through the lymph system or blood vessels to reach different parts of the body (Sampson 1925, Sampson 1927). This theory does not explain the cases of endometriosis in men as usually men do not have a uterine lining, or those cases of endometriosis found in the brain as lymphatic and haematogenous spread would not explain endometriosis implants crossing the blood brain barrier (a barrier that limits what can access the brain).

The third theory, the Coelomic Metaplasia Theory, suggests that endometriosis is caused by metaplastic change of mesothelial cells into endometrial implants (Gruenwald 1942). This theory may help explain reported cases of endometrial implants within the lungs and the brain, but does not explain its predominance in women, as both

men and women have mesothelial cells (Fritz 2005). The fourth theory, the Embryonic Rest Theory, hypothesizes that certain stimuli may induce cells of mullerian origin to become endometrial tissue. Mullerian ducts are embryonic structures that give rise to female reproductive organs. This would favour effectively more women than men, as women are born with more mullerian tissue than men, but remains non-specific as to the stimuli (Russell 1899).

While the cause of endometriosis remains unclear, susceptibility to endometriosis has been linked to a combination of genetic, immunologic, hormonal, and environmental factors (Crosignani et al 2006). It is also thought that altered angiogenesis (blood vessel growth) and apoptosis (cell death) may contribute to the pathogenesis of endometriosis (Bulun 2009). It has been shown that endometriotic tissue produces increased levels of the enzymes Cox-2 and aromatase which in turn increase prostaglandin levels compared to normal endometrium (Bulun et al 2005). Several review articles have pointed out that endometriosis is a chronic inflammatory disease, and the chronic inflammation has been considered to be a major cause of pain in endometriosis (Vercellini et al 2008), linked to the propagation of the disease (Becker and D'Amato 2007). However, despite calls to begin viewing endometriosis as a rheumatologic condition, it is still primarily considered a gynaecological disease of women, leaving endometriosis invariably linked to the uterus and menstruation, a topic we will come back to in Chapter 5.

Debate continues in the medical community as to the 'true' existence of endometriosis, and it hinges on several issues. Endometriosis implants have been found in women who have no complaints about the disease (Woodward et al 2001). As stated before, there is little direct correlation between endometriosis pain and the number of endometriosis implants. The pathophysiology of endometriosis and associated pain symptoms is not well understood. Nerve fibres have been identified in endometriotic lesions (Tamburro et al 2003, Tokushige et al 2006a, 2007 in Wang et al 2009) with implants developing their own sensory and sympathetic nerve supply (Berkley et al. 2004, 2005 in Wang et al 2009). The density of nerve fibres in the peritoneum was found to be increased in women with endometriosis as compared to women without endometriosis (Tokushige et

al 2006b in Wang et al 2009). In women with Deep Infiltrating Endometriosis (DIE), a sub-type of endometriosis where lesions infiltrate more than 5mm into the pelvic wall or retroperitoneal space (Wang et al 2009), pain has been accurately linked by location to specific symptoms (Fauconnier et al 2002, Vercellini et al 2008) and to increased pain in comparison to other forms of endometriosis (Wang et al 2009). Thus, the connection between the visualised implants and the complaints of women with the disease is not simple. This lack of direct connection complicates the meaning of the diagnosis and interferes with treatment planning.

V. Treatment of Endometriosis

Treatments of endometriosis derive from these recent diagnostic histories and can be either through medical or surgical means. Generally, the surgical treatment of endometriosis aims at eliminating endometriotic implants, and decreasing pain (Redwine 2004). Laparoscopy (keyhole surgery) is considered a first line of intervention; hysterectomy is generally thought to be a far more serious intervention because of its effect on fertility and questions remain as to its usefulness. A secondary class of intervention includes presacral neurectomy and Laparoscopic Uterosacral Nerve Ablation (LUNA) and is aimed at decreasing pain.

Medical treatment involves primarily either hormonal treatments or medications that decrease pain. The main hormonal treatments available for endometriosis include oral contraceptives, progestins, Gonadotropin Releasing Hormone (GnRH) –agonists and androgenic agents. These treatments are all associated with high recurrence rates after the treatment is stopped (Hompes and Mijatovic 2007). For treatment of chronic pelvic pain associated with endometriosis, nonsteroidal anti-inflammatory drugs, such as ibuprofen or mefenamic acid, have been used (Valle 2002, Wieser et al 2007) with only partial benefit (Evans et al 2007). Amitriptyline (an antidepressant drug) and gabapentin (also called Neurontin) are used to control seizures and relieve nerve pain) may be beneficial (Sator-Katzenschlager et al 2005). In addition, studies have shown aromatase inhibitors to be effective in endometriosis treatment. Aromatase inhibitors block the enzyme aromatase which transforms the androgen hormone into small amounts of

oestrogen. However, their use is still considered investigational, as they have yet to be approved by the Federal Drug Administration (FDA) for this indication (Practice Committee of ASRM 2006a, Practice Committee of ASRM 2006b).

Hormonal treatment of endometriosis is justified by the notion that ectopic endometriosis cells are related to the uterine lining with the assumption that endometriosis implants will react in the same way that the uterine lining does. The goal is to stop menstruation in women with endometriosis, which presupposes that endometriosis implants can be manipulated in a similar fashion. Thus, the mainstay of medical treatment for endometriosis is focussed on hormonal therapy to alter the normal menstrual cycle during the reproductive years (Fritz 2005). The rationale for this type of treatment is to decrease cyclic menstruation with hopes of reducing peritoneal seeding, to slow the growth and activity of the eutopic endometrium, and as a result decrease the formation of ectopic implants (Fritz 2005, Mounsey et al 2006). The main hormonal treatments available for endometriosis include oral contraceptives, progestins, Gonadotropin Releasing Hormone (GnRH) – agonists and androgenic agents. These interventions are all associated with high recurrence rates after the treatment is stopped (Hompes and Mijatovic 2007), and research suggests that potential treatments linked to rheumatology have promise (Bulun et al 2005, Bulun 2009). Focus on hormonal treatments remains common, as I will discuss in more detail in Chapter 5.

Other treatments being suggested for endometriosis currently, such as pregnancy and hysterectomy, remain remarkably similar to the past views of how to treat problems with the uterus or 'furor uteri'. The surgical option of hysterectomy as a cure, despite much medical literature that suggests this is largely unsuccessful, remains common. Thus, the current practice of taking out the uterus is connected to notions of the 'wandering uterus'. Is the uterus still considered the cause of all of the problems despite the unclear link between the uterus and endometriosis? Why is this treatment still so prevalent? I will return to this question in Chapter 5.

There are other echoes of the past in treatments for endometriosis. For example, the suggestion of pregnancy as a cure, this time for endometriosis, is noted in an article written by Joe Vincent Meigs, M.D. in 1953:

> The best medical treatment for endometriosis is pregnancy. During pregnancy growth ceases and occasionally, during lactation, activity is absent. However, pregnancy cannot be used as treatment in all cases; conception is not always possible and the patients may be such as to make it unwise (Meigs 1953: 50).

Note from Meigs' article the concept of preventing endometriosis through pregnancy. He showed a clear adherence to previous perceptions of women wherein their main role was reproduction. He explained that:

> For women to have children and fulfil their reproductive role is physiologically normal; 12-14 years of menstrual life without interruption is not. In a woman who is leading a normal, married life, periods may be infrequent (Meigs 1953: 47).

The notion of a 'normal' life as synonymous with a 'married life,' is remarkably similar to current ideas about stigma connected to childlessness. Meigs used this concept to bolster marriage and pregnancy as preventive measures against endometriosis.

> It is this author's belief that avoidance of endometriosis through early marriage and frequent child-bearing is the most important method of prophylaxis. …The ultimate object of marriage is to have children. It is obvious that endometriosis does have a very definite effect on fertility (Meigs 1953: 49).

Here there is a plea for the preventive interventions of marriage and pregnancy reinforcing the notion of endometriosis as 'The Career Woman's Disease' (Capek 2000, Shohat 1998). The 'Career Woman' contradicts routine family values and prioritises procreation over other pursuits (Capek 2000). Thus, to prevent the 'Career Woman's Disease', one must marry early.

Meigs' text also emphasized two notions that come up again in current medical thinking about endometriosis. First, he wrote that 'endometriosis usually occurs at the age of 26 or later' implying endometriosis did not affect teenagers.

> Therefore, since endometriosis usually occurs at the age of 26 or later, and since the later-marrying private cases in all three of our series had a larger percentage of endometriosis, it would seem advisable to urge earlier marriage (Meigs 1953:49).

This idea persists to this day, with guidelines on endometriosis and clinicians appearing to stick to this concept despite medical evidence to the contrary. This issue also becomes particularly important within women's diagnostic trajectories, ultimately contributing to women's struggle for a singular endometriosis label.

Second, Meigs' focus on a woman's fertility paralleled, above all else, findings in this thesis where women felt that their symptoms of endometriosis were taken seriously only after they sought to have children.

> After a woman has her children and she grows older, pathologic lesions such as endometriosis or fibroids may develop; but if the advice were heeded, these would come after the children had been borne. Thus if children are borne early in life, endometriosis is less likely to interfere with future fertility (Meigs 1953:49).

Such notions of non-pregnancy or delayed pregnancy being abnormal for women have been taken up again recently in evolutionary medicine, suggesting that decreased pregnancies lead to women's health issues, including increased reproductive cancers in the West (Bulbrook 1991, Sievert 2008, Henderson et al 1993, Maynard Smith et al 1999).

Not only do theories about the 'wandering uterus' and its associated treatments permeate current clinical discourse on endometriosis, they limit who can be considered to have endometriosis (with endometriosis still considered the 'career-woman's disease') (Shohat 1998, Capek 2000, Whelan 2009). Ultimately, such social understandings of the role of women continue to permeate medical discourse such that women struggle to receive the endometriosis label, and the diagnostic category of endometriosis remains under threat and at the same time stuck as a gynaecological disease of reproductive-aged women.

Owing to the continuation of social and economic understandings of women's roles and persisting notions of women's bodies such as the normality of pain during menstruation, the diagnostic category of endometriosis is still questioned today. Women with endometriosis still report being told that their pain is simply 'normal period pain' or that

they were sent to a psychiatrist as their symptoms suggested a mental illness as opposed to a physical illness. This parallels historical notions from the 1970s where pain with menstruation remained something normalised, but it was no longer acceptable to give in to this pain. Staying in bed during a menstrual cycle was at this time linked to a specific psychology. Painful menstruation and the pain of impending delivery of a child were linked to psychogenic factors that had the ability to both cause and worsen such symptoms.

> Dysmennorhea [menstrual cramps], nausea of pregnancy, pain in labor and infantile behavioral are conditions commonly considered to be caused or aggravated by psychogenic factors (Lennane and Lennane 1973: 288 in Ehrenreich and English 2011: 147).

The endometriosis diagnostic category thus remains contested or threatened by the persisting historical notions of women's bodies that are seen as normal in their abnormality. Any complaints by women linked to what is seen as painful menstruation, as in the case of endometriosis, may be dismissed or pushed on into the a-diagnostic category with its link to mental illness.

The concept of menstruation as ill health blurs the difference between 'normal' menstruation, dysmenorrhoea, and symptoms of endometriosis. Notions of what is a normal period, what is considered dysmenorrhoea, and what is considered symptoms of endometriosis are unclear both to women with endometriosis and to doctors. Instead, there is a separation between symptoms that may be due to endometriosis and the physical, visible signs of endometriosis as seen through microscopy or during a surgical procedure. This split is not new but appears to originate from the first descriptions of endometriosis. And with endometriosis symptoms often non-specific and the tenuous link between visualized endometriosis and its symptoms, women with endometriosis often report common experiences of being told that their symptoms are 'All in Your Head' (Griffith 2009), with endometriosis being dismissed as psychosomatic (Seear 2014). This dismissal of endometriosis as psychosomatic speaks to the shift from seeing women's bodies as physically ill to mentally ill especially when complaining of menstrual pain (Seear 2014). I discuss this in more detail throughout the thesis in various chapters because this notion links endometriosis to stigma, to why women use

control strategies with their doctors, to the role of the various endometriosis support groups in the United Kingdom, and of course to diagnostic trajectories women experience with their struggle to escape the a-diagnostic category and receive the endometriosis diagnosis.

VI. Conclusion

I have argued in this chapter that the gendered history of menstruation continues to impact current concepts of endometriosis. The contested nature of endometriosis as a diagnostic category through, for example, questions about the links between the number of implants and the related severity of symptoms is well known. This has perpetuated multiple understandings of endometriosis and means that longstanding discourse about normal menstrual pain continues. The idea of menstruation as inherently painful and the more recent notion that complaints about menstruation are linked to psychological issues open the door to further questioning of the diagnosis, and to the positioning of women in the a-diagnostic category.

Clinical care of women with endometriosis often still reflects a view of menstruation that affects their ability to access care and to receive a timely diagnosis. The differences among menstruation, dysmenorrhoea, and endometriosis are blurred because of historical and present-day notions of painful menstruation. This results in difficulties for both the giving and receiving of an endometriosis diagnosis. The a-diagnostic category in endometriosis care stems from the long history of menstruation as 'normally painful'.

The historical notions I have articulated in this chapter continue to act upon and be incorporated into biomedical understandings of endometriosis and affect the a-diagnostic category. Women struggle to receive a diagnosis of endometriosis with their symptoms often still interpreted as 'normal period pain', or various mental health issues.

CHAPTER 4

The Search for a Unitary Endometriosis Label

I. Introduction

The last chapter examined how historical notions of menstruation still play out in the present day enactments of endometriosis. Ideas of menstruation as normally painful affect the recognition of endometriosis as a condition easily differentiated from the 'normal period', for example. The a-diagnostic category emerges as women are often unable to access a diagnosis while labelled with non-medicalised conditions such as 'normal period pain'. The a-diagnostic category becomes important, leaving the endometriosis label notoriously hard to access. In this chapter, I present the different pathways women took in their journey towards achieving the diagnosis of endometriosis. For some, the pathway was prolonged by a long detour through what I am calling the a-diagnostic category. But many achieved the unitary diagnosis and escaped the a-diagnostic category, while still having to confront the after-effects of finally receiving the diagnosis. I discuss what women saw as the effects of remaining in the a-diagnostic category.

The struggle to receive the diagnosis of endometriosis has been clearly documented in both biomedical literature (Ballard et al 2006, Hadfield et al 1996, Husby et al 2003, Pugsley and Ballard 2007) with the length of diagnosis across the world averaged at 7-10 years until diagnosis (Johnston et al 2015) and discussed in qualitative literature (Denny and Mann 2008, Manderson et al 2008, Markovic et al 2008, Seear 2009b, Santos et al 2012).

Women in my study spoke of GPs as gatekeepers who often did not acknowledge the possibility of endometriosis for years and instead considered only alternative non-medicalised explanations for the women's symptoms. Thus, the women were not diagnosed as having endometriosis, and the result was they found themselves in a social position I am calling the a-diagnostic category. All the women in my study described this experience. Some noted that the 'dismissal' of their complaints came not only from medical professionals but also from lay persons such as their mothers. Symptoms were accounted for by resorting to explanations such as 'bowel pain', the 'norm', non-specific psychiatric illness, or an allergy to food colourings. The longer a woman

stayed in the a-diagnostic category, the longer the time was to her being eventually diagnosed with endometriosis. Women regularly saw this experience as a dismissal from the healthcare system and as being 'fobbed off'.

This long-term categorisation underlined their struggle to receive the diagnosis of endometriosis. The women reported three general paths to diagnosis: incidental diagnosis, self-diagnosis, and a long-time route to diagnosis that involved multiple visits to doctors. In each pathway, they described difficulty in obtaining the diagnostic label and having their history of symptoms believed.

Once diagnosis was achieved, it allowed patients to take on the sick role more successfully (Parsons 1951). Endometriosis is, of course, not unusual in this way. It was easy to see that individuals, who vigorously and repeatedly described their health complaints to their doctors were relieved when the doctors explained the nature of the problem and the potential solutions. The diagnosis of endometriosis helped women's complaints gain legitimacy with doctors. That, in turn, facilitated transfer from the a-diagnostic category and catalysed access to a plan of care and treatment that limited the effect of endometriosis on personal relationships and fertility (Denny 2004, Denny 2009, Cox et al 2003b, Manderson et al 2008, Santos et al 2012). The label also allowed for participation in a form of biological citizenship (Rabinow 1996), as the women with endometriosis felt more a part of an organized system of care and thereby less isolated. However, the attainment of the label came not only with positive but negative aspects. With diagnosis came an obligation to participate in the treatment planning, to get better (Novas and Rose 2000, Parsons 1951), and for knowledge acquisition that would enhance their care. A diagnosis of endometriosis put the onus of responsibility on the women with endometriosis to demonstrate their commitment to remain in the diagnostic category. They reported being expected to research the term endometriosis themselves.

II. The A-Diagnostic Category

The importance of the concept of what I am calling the a-diagnostic category within endometriosis circles cannot be emphasized enough. Every woman I spoke to had some experience of the a-diagnostic category, and the notion of being 'misdiagnosed' was prevalent. Figure 4.1 addresses the importance of this topic within the endometriosis community. The figure speaks to this concept of 'common endometriosis misdiagnoses', and may have been the most common image related to endometriosis I came across online. It appeared frequently, in various colour schemes, on several endometriosis-associated online groups and was posted repeatedly by different women. This reinforces how important it was for the endometriosis community when someone could not access the endometriosis label and remained in the a-diagnostic category.

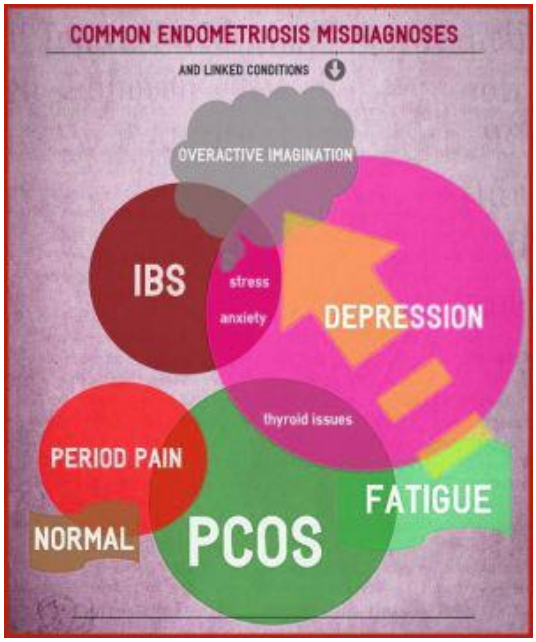


Figure 4.1

Common endometriosis misdiagnoses

The a-diagnostic category related to endometriosis, as Figure 4.1 shows, includes a collection of labels used for patient complaints before the patient is finally diagnosed as

having endometriosis. The labels include: 'Normal', 'Period Pain,' 'Fatigue,' 'Depression,' 'Stress,' 'Anxiety,' and an 'Overactive Imagination'. The list also encompasses traditional differential diagnoses of endometriosis such as IBS (Irritable Bowel Syndrome), and PID (Pelvic Inflammatory Disease). Use of these labels often interferes with establishing the diagnosis of endometriosis. Each woman with endometriosis I spoke to reported multiple experiences of being considered to have one of the ailments on the list noted on Figure 4.1.

Women with endometriosis not only experienced this dismissal of symptoms by doctors, but also by relatives such as their mothers. Judith, for example, explained that her endometriosis symptoms were taken to be '*bowel cramps*' by her mother. Judith did not realize that her symptoms could be related to endometriosis, despite her mother's own history of diagnosed endometriosis.

> *I have had symptoms of endometriosis since my late teens. However, I did not know they were endometriosis symptoms. I told my mum about them and she said they were probably 'bowel cramps'. Incidentally, my mother had been diagnosed with endometriosis after having a laparoscopy in her late thirties when she started to suffer from abdominal pain. The symptoms I had (and my mum misinterpreted as bowel cramps) were a sharp pain like being stabbed with a knife through my abdomen. It was so bad I had to sit down, but would pass quickly. Another symptom I had since my teens was feeling very nauseated and weak when I was hungry. I always had to eat very regularly, or else the hunger would come very suddenly sometimes rendering me completely helpless and close to fainting*.-Q

On the other hand, Alice spoke of how her symptoms, were seen as normal by both doctors and her mother. She explained that at the age of twelve, when she first began menstruating, her symptoms were '*seen as the norm'*. She went on to explain that:

> *By 15, I think my symptoms had begun to get so bad where I was feeling faint all the time with the pain. The pain was starting to get bad; the bleeding was very heavy with clotting as gross as that sounds. So that's when it started picking up. And again it was put down to well you've just got heavy periods. The doctors didn't seem to think anything of it, anything special about it it's just heavy bleeding*.-SSI

She received two separate interpretations of her symptoms. First, she was told that it was the '*norm*'; then as the acknowledgement came that her symptoms were in fact

abnormal, the explanation moved on to be about '*heavy periods*'. Even with this new 'abnormal state', it was seen as acceptable. It was not something to be treated, but rather a fact simply to be noted.

Norah, in contrast, was first thought to have chronic fatigue syndrome. This 'working diagnosis' was then transformed into the notion that she had an allergy to orange and red food colouring, which was causing both her 'stomach pain' and her fatigue:

> *I also got looked at as to whether I had um some kind of chronic fatigue as a teenager. Very tired all the time everybody else would go out and do things. And I just wanted to sleep in the house basically. And a GP that I don't really remember a lot of this but my mum told me that a GP we went to see had a daughter who was allergic to food colourings and decided that it was an allergy to sort of orange and red e numbers basically and that what it was. Didn't look into just decided because his daughter had it that's what it was. Which confused me cause I always thought it would tend to make you more hyperactive if you were allergic to food colourings whereas I used to get a lot of stomach pains and very, very tired to the point where, like I said, just couldn't get off the couch. Just wanted to sleep all the time*-SSI

In addition, several women with endometriosis experienced being sent to a psychiatrist. Jenny, for example, explained that she learned not to complain anymore. She was told that she was not in pain, and that she would just have to keep going back to the psychiatrist until she no longer complained of being in pain. As a result, it took her years before she sought help again as a result.

All of my participants reported problems with not being believed by doctors. As seen above, many simply visited their GPs with symptoms linked to endometriosis and were either given advice that indicated the doctor had not heard their complaints or they were told their symptoms were 'normal'. Ultimately, being attributed one of the differential diagnoses by a GP resulted in women often feeling that they were not believed. Thus, the experience of being 'fobbed off' was quite common amongst my participants [3]. Martha explained that for her:

[3] 'Fobbed off' is a British expression that denotes 'to put off with a trick, excuse or inferior substitute' (Merriam-Webster Dictionary 2016).

> *At first it was a lot of fobbing off - either by men who just didn't get it, or by women who were even worse (their periods didn't hurt, so they refused to believe mine did - I was being soft or attention-seeking, right?) All I was offered was either 'take some paracetamol' or 'go on the pill' - and the pill didn't suit me and caused cervical erosion and more bleeding, so that had to be knocked on the head as well. As I say, after a couple more years of trying to get somewhere I gave up for ages, although in my mid-twenties, in desperation, I tried once more and got a breakthrough with a motherly lady who tried me on the mefenamic acid, bless her. With a partial fix achieved I didn't bother again until I had the fertility issues*.-Q

Because of these combined experiences of being 'fobbed off' and using medication that made her symptoms worse, Martha gave up on receiving help from the medical community. She explained that it was only in her mid-twenties that she returned again to see a doctor. She was given mefenamic acid that partially alleviated her symptoms. She stayed away from looking for more answers until she began trying to have a child. It was at this point that she was referred to a fertility clinic. Until that time, she had yet to see a gynaecologist for symptoms that began in her teenage years. However, being referred to the fertility clinic did not allow Martha to access a diagnosis immediately. Instead, she was first given Clomid (a medication to treat fertility) for three months. It was only when this treatment failed that she was offered, albeit 'reluctantly', a laparoscopy which then showed endometriosis.

> *At that time I got a referral to the fertility clinic, but I think they were running through the options cheapest first, so I was immediately stuck on Clomid for three months - which obviously didn't have a hope in hell of working through blocked tubes! - before I was told, rather reluctantly, "I suppose we better give you a laparoscopy and see if there's something else going on". That was the second breakthrough - my consultant from that point on was amazing - I finally got my diagnosis (aged 35!) and he tried his best to effect some sort of repair job. When that failed he got me fast-tracked onto the IVF list in view of my age, and the rest is history. We did save a pot of cash and try for a second child privately, but by then I was 40 and really knew it was a no-hoper.*-Q

While in many cases a product of a change in circumstances, such as a shift to another medical professional, movement from the a-diagnostic category still represents not only a struggle but also a real inability to access care, often to the detriment of the women's health. This often meant that it was effectively too late to do anything, at least in terms of fertility, as in Martha's case.

In many cases, this experience of being 'fobbed off' marked placement in the a-diagnostic category, with explanations often linked to 'normal' periods or psychiatric issues. This is, of course, highly reminiscent of past understandings of painful menstruation as normal, or the 'wandering uterus' and its associations with demon-possession. Thus, the a-diagnostic category of endometriosis remains inescapably linked to historical notions of the woman's body as 'unruly' and the need for the uterus to be 'tamed'.

III. Negative Effects of Remaining in the A-Diagnostic Category

Such experiences of being moved in an a-diagnostic category were not only common, they were seen as negative. Returning to Figure 4.1 for a moment, its title 'endometriosis misdiagnoses' implies that the a-diagnostic category is seen by women as a mistake, an error, with a subtext that doctors are the ones who have erred here. Lengthened diagnosis and treatment times due to inclusion in the a-diagnostic category were seen as directly impacting women's health, as the a-diagnostic category was often associated with a dismissal from the healthcare system. In addition, inclusion in the a-diagnostic category and being 'fobbed off' appeared to affect self-confidence and to create feelings of personal failure and weakness, as women worried they were not dealing appropriately with their pain.

A. Lengthened Times to Diagnosis and Treatment

Not receiving a diagnosis and remaining in the a-diagnostic category meant women were unable to access care related to their condition. It is not surprising that all women with endometriosis in my study emphasized the need for increased access to diagnosis, because delayed diagnosis times were linked to worsening endometriosis symptoms. For them, a lack of diagnosis would lead to increased pain, multiple surgeries, and more adhesions (scar tissue), and generally worse outcomes both in terms of pain and infertility. This echoes previous research that found that women with endometriosis

'believe disease becomes progressively more severe and therefore more difficult to treat the longer it is left undiagnosed' (Hadfield et al 1996: 878).

Marie, for example, begins by stating that:

> *I would have quite liked to be told [endo] existed!!! And then to have been investigated/diagnosed a lot earlier - yes, the investigation is invasive, but if you're in that much pain you would accept that, wouldn't you?*-Q

If her condition had been investigated and diagnosed earlier, the pain she experienced may have been limited. While she acknowledged that diagnosis of endometriosis remains invasive, she maintained that one would be willing to take such a risk to get a diagnosis and decrease one's level of pain. The escape from the a-diagnostic category remains at the forefront then, as a diagnosis may help decrease the suffering women experience.

Earlier access to the endometriosis label may have led to a different clinical outcome and also a change in life trajectory. Several women stated that if they had had earlier knowledge of endometriosis and its association with infertility, their decision-making would have changed. Marie, for example, suggested that if she had known about her endometriosis, she would likely have begun trying to have a family earlier.

> *If I'd known in my t[w]enties that I had the condition I would have started trying for a family sooner - possibly before my tubes were irrevocably damaged, or if already too late then I could have started IVF sooner, had more time to save up for subsequent cycles, and potentially have had more children with a better success rate due to younger age.*-Q

Without a diagnosis, she did not realize the implications of endometriosis. She might have tried to get pregnant earlier and at the very least she would have begun saving money for IVF treatment. Being fixed in the a-diagnostic category had serious consequences for not only care. The associated physical symptoms and the quality of life of women with endometriosis also may have a profound impact on a woman's chosen life trajectory.

B. The A-Diagnostic Category as a Dismissal from the Health-Care System

The use of the a-diagnostic category by health-care professionals was also seen as a way for women to be dismissed from the medical system. Robyn explained that:

> *Diagnosis methods urgently need to be improved. Doctors are very reluctant to do laparoscopy (due to expense I'm sure) and yet this is the only current method of definite diagnosis. So we are fobbed off for a long time before getting a diagnosis. There is a lot of 'yes, periods hurt, it's just part of being a woman' which needs to be dropped. Doctors should be able to give a lot more advice on self-care and natural ways of alleviating symptoms rather than immediately prescribing cheap contraceptive hormones and hoping we will go away.*-Q

While Robyn linked limited diagnostic tools to delayed time to diagnosis and ultimately increased time in which women experience being 'fobbed off', she also talked about a common way in which symptoms of endometriosis are associated with the a-diagnostic category: the notion that 'yes, periods hurt'. Women felt that doctors were reluctant to look for a diagnosis and actually hoped patients would stop bothering them and 'go away'. Many women echoed this feeling. Thus, entering the a-diagnostic category and then confronting the difficulty in getting out of it defined a process that women saw as a confrontational position on the part of the doctor, who was trying to force women out of the medical system.

This confrontation was also experienced in the context where doctors or the medical community effectively abandoned women in their time of need. Women with endometriosis reported that gynaecologists gave up on them when they were unsure of what to do to solve their problems, even after the diagnosis was made. While in this chapter, I focus primarily on the a-diagnostic category before diagnosis, I want to point out that this sense of abandonment by medical professionals is something that women discussed before and after the diagnosis of endometriosis was made. Emergence from the a-diagnostic category after diagnosis is a topic I confront in the next two chapters. It influences on the enactments of endometriosis in the gynaecology clinic.

C. I Have Been Fobbed Off

Finding themselves in the a-diagnostic category also meant that many women felt that they were not seen as credible and were 'fobbed off', an experience all of my participants described. The symptoms they presented with were discounted, and everyone doubted their pain level. Alice explained that:

> *I cannot think of any other way doctors could make the treatment itself better but some doctors could improve their patient rapport I suppose if they were able to listen more and to believe what the patient was saying to take what the patient was saying as being true. There is nothing worse than when you're disbelieved or they doubt your level of pain.*-SSI

This common experience was a source of stress. The women did not know what was causing their symptoms, and the lack of a diagnosis contributed to their feeling that their symptoms were 'all in their head'. Consequently, the a-diagnostic category was therefore associated with self-doubt and decreasing self-confidence. Sally reported that:

> *It was awful. Knocked my confidence in myself and in the doctors. At 16 years old I got told I had been to the doctors that year 33 times with the same problem and that there was nothing wrong. I got told it was in my head and refe[r]red to a shrink! I was even starting to doubt myself. I had no support from them at all and even now at 37 I still feel angry about how I was treated. The doctors at the hospital were very different. It was like a weight lifted off my shoulders to finally know what was wrong. Then an even bigger weight back on them when I realised it wasn't going to go away. I do think though that I wasn't given enough info in the early days. An information pack on diagnosis would be a good idea.*-Q

Before a diagnosis was established, she was told her symptoms were 'all in her head'. This affected her self-confidence, and as a result, she began to doubt herself. This narrative of being sent to the psychiatrist before being diagnosed was a common occurrence.

D. Suffering as Weakness and Personal Failure

Remaining in the a-diagnostic category, with its common links to mental health and the notions of 'it's all in your head' and 'normal period pain', often led to women feeling that they were somehow 'weak' compared to others. They felt that letting pain have

such a profound effect on their lives confirmed the weakness. Because of the long times to diagnosis, many women understood their suffering as a personal failure, an issue noted previously by Manderson et al (2008). While this feeling was in large part linked to experiences as seen above of women being told 'they are normal' or that 'it's all in their head', women with endometriosis also linked these feelings of weakness to not having a diagnosis. Membership in the a-diagnostic category and the associated delay in diagnosis meant then that women asked themselves whether they were somehow unable to deal with mundane life problems such as 'normal' levels of pain.

Catherine, for example, explained that: '*You start thinking you are a bit of a sissy'*-SSI. The result is that you start to think that *'it must be me being a bit soft – so I'll just put up with It'*-SSI. Ironically, this feeling of being weak led women to think they should continue to deal with the pain on their own, and they sought help less often. Also, some women concluded that it was their *' lot to suffer*'-F, and as a result, doctors would not or could not help them. Increased visits to the doctor without having a diagnosis reinforced this notion of being weak. Women with endometriosis spoke of how multiple visits to the clinic without any diagnosis or referral led to questions about whether *'I am being a strong woman* or *am I weak – is that why this affects me more than other women'?*-F

Staying in the a-diagnostic category seemed incompatible with access to the sick role (Parson 1951). The inability to access the endometriosis label had practical implications. Women began to judge themselves, feeling they did not live up to demands of a 'productive' life. They considered themselves unable to face up to pain while going about the usual activities of daily living. In some cases, individuals waited longer to seek care because they had come to believe they were struggling with a personal failing, not a medical problem. Being positioned in the a-diagnostic category implied for some women that they did not have a somatic[4] condition, but instead they lacked control of their emotions and needed to fix this. Hence, there was a subtle

[4] Somatic – 'Pertaining to the body (soma) as opposed to the mind (psyche)' (Collins Dictionary of Medicine 2005).

transformation of these complaints focused on the body into complaints that represented preoccupation with the psychological sphere.

IV. The Struggle for Diagnosis

The importance of diagnosis lay not only in the biomedical task of organizing symptoms into an identifiable syndrome that allowed formulation of a treatment plan. Diagnosis also contributed to limiting women's negative experiences with their doctors. Diagnosis helps women to feel heard, so that they could avoid the sense of being categorized as simply formulating complaints in their heads that had no real grounding in other bodily disorders. For women, the ability to access the endometriosis label became important, which explains why so many women in my study spoke of the struggle to gain a diagnosis of endometriosis. Three separate narratives around diagnosis were put forward by the women: the long quest to diagnosis; the incidental diagnosis; the self-diagnosis. While these three pathways to a diagnosis differ, each one illustrates the work necessary to overcome the hurdles encountered along the road to the endometriosis label.

A. The Long Quest to Diagnosis

The long route to diagnosis, while by far the one most commonly experienced by women with endometriosis, required the most struggle. Women described it as a fight to be heard and to be taken seriously. The extended work to reach a diagnosis was caused primarily by being side-tracked into the a-diagnostic category.

Women with endometriosis often spoke of GPs as a professional group that guarded the gate of access to the diagnosis of endometriosis. GPs kept the women from being referred to specialist gynaecologists who controlled issuance of the diagnostic label. Women spoke regularly of the ultimate power GPs had in determining how women proceeded along the pathway, and also of the GPs' influence over how women were moved into the a-diagnostic category. For many women, it was only by going around

the GP that they were able to obtain a referral to a gynaecologist who ultimately made the diagnosis.

Women reported several methods of circumventing their GPs. These included being referred by a practice nurse, seeing a gynaecologist in hospital, switching GPs because of a move across the country, all unintentional ways by which they ultimately accessed specialist care. Only one woman with greater financial means was able to implement the one intentional way to bypass her GP. She sought private care outside of the NHS.

Alice explained it was not until she saw a practice nurse, while attending university, and explained her symptoms that she was ultimately referred to a gynaecologist. She had struggled with endometriosis symptoms since she first got her period at age 13 and had seen the same GP for years, with no forward movement.

> *No tests were done until I was at university. So when I was 18, 19. By that time I was also ill all the time –I was run down – I had had tonsillitis all my life really. Well I was under a really good nurse at university anyway because of the tonsillitis and things – and she referred me back to my own doctors to consider a tonsillectomy. And it was through her I started telling her about my other symptoms as well. Can you do anything for this the bleeding and the pain? And she referred me to a specialist in the end.*-SSI

Sally stated that her diagnosis only came after being under the care of a gynaecologist in hospital that she was able to begin the route towards a diagnosis. Her 'local doctors', including her GP, avoided making a referral to specialty care and put 'her symptoms down as psychosomatic'.

> *I first had symptoms about a year and a half after starting my periods. I started age 12. I was not diagnosed until I was 21 years old. I only got that diagnosis because I was under gynae at the hospital and mentioned to them about all my problems. My local doctors had my symptoms down as phycosematic!!! Not sure if I spelt that right sorry.*-Q

Magda recounted how she was unable ever to get her GP to refer her to a gynaecologist. This eventually forced her to seek care outside of the NHS. She saw a private gynaecologist. She explained that after this it was relatively easy for her to receive a laparoscopy, but that she had to be her own advocate and push to receive a diagnosis

that clarified things. This lateral move outside of NHS may represent a protest against the organised care system run by the NHS. Of course, it is not clear why the GP was not willing to refer her to specialty care. She therefore had to take action and force that referral in anyway she could. This lateral move outside of their current medical system, the NHS, was one sought by other women but often it was not a financially viable move. Many other women with endometriosis would have liked to follow Magda's path, but were unable financially to get private care.

Mol (2008) has reminded us that the elaborate rules dictated by public sector systems like the NHS serve sometimes to limit the patient's choice of care. They may also diminish the improvements in care that one might hope to introduce into the system through the administrative rules. An additional point is that 'gatekeeping' is a common technique in organized medical systems. Individuals who watch the gate are often charged to decrease the cost of care. As a result, the GPs should not be seen as wholely at fault for the system-wide pressures.

In addition, GPs effectively influenced women to do research into how to get past the GP obstacle. One common form of such research came to light in support group meetings where women with endometriosis spoke at length about how to get their GPs to refer them to a gynaecologist. This included not only discussions of first referrals but also repeat referrals back to a specialist. For example, Lorrie stated

> 'so what is the best way to get referred to gynaecology? Is it possible to get referred to a specific gynaecologist?'- F

Practical notions about gaining access to care predominated in support group meetings as well as in their online equivalent. This suggests these issues are of vital importance to accessing care.

B. Incidental Diagnosis

Several women described being diagnosed incidentally[5] through a laparoscopy (keyhole surgery) done for another reason. These individuals did not feel that they struggled to receive the initial diagnosis of endometriosis. Instead, the struggle came later, after the original diagnosis did not bring with it a particular line of treatment or even acknowledgment of a link between the diagnosis and symptoms the women may have experienced. They still felt, however, that it became their responsibility to proceed to treatment based on this new diagnosis, and often to reinforce effectively the endometriosis diagnosis. Despite officially moving out the a-diagnostic category with access to the new label through incidental diagnosis, in fact the escape from the a-diagnostic category only came after access to treatment protocols related to endometriosis.

Rachel pointed this out:

> *I was first diagnosed "accidentally" when I had an emergency laparoscopy for an ovarian torsion/dermoid cyst (2010, aged 34). The surgeon told me afterwards that she'd seen endo spots. I'd had a lot of pelvic pain and irregular bleeding prior to this but am still not sure whether the symptoms were more to do with the dermoid and destroyed ovary than they were to do with the endo.*-Q

Her accidental diagnosis was related to an emergency laparoscopy and therefore was not at all expected. Since this 'accidental' diagnosis occurred at a time when another health condition took precedence because if its gravity, it was possibly overlooked, with doctors seeing endometriosis as both clinically unrelated and not as important as the dermoid cyst. She also appeared unsure whether to attribute her symptoms to the dermoid cyst or to endometriosis. She received two diagnoses at the same time. Pragmatics were dominant here as clinicians looked to deal with the more urgent problem at hand and left the other incidental diagnosis (in this case endometriosis) as secondary. Thus, individuals in this pathway to incidental diagnosis of endometriosis lacked the antecedent history of the disease linked to those in the long quest pathway. Consequently, those who were given the diagnosis incidentally did not find the kind of

[5] An incidental diagnosis is a previously unrecognized medical condition that is discovered unintentionally.

relief enjoyed by the long quest group once the diagnosis was made. I discuss this finding more extensively in the next chapter. In those with the incidental diagnosis, it was not even clear whether the symptoms were in fact due to endometriosis. As a result, receiving the diagnosis in this instance was not connected to escape from the a-diagnostic category.

Rachel did ultimately look for a confirmation of her endometriosis diagnosis because of a change in her symptoms. She explained that:

> *Anyway, I was "lucky" enough to be able to take this surgical diagnosis to my Dr when I went with symptoms of continuing pelvic pain. I had a further laparoscopy to treat endometriosis spots and determine the extent of the endo in 2011, at which point the previous "accidental" diagnosis was confirmed. My symptoms generally are of pain, and now moderately heavy periods. Prior to my early 30s I had never had problems with periods.*-Q

However, even with this diagnosis in hand, it seems that the onus was put on her to obtain follow-up treatment. Rachel explained that she had to take the diagnosis to her doctor herself. The label did not appear to mean much on its own to her doctors. 'Seeing endo spots' did not translate to any treatment related to endometriosis and needed to be 'confirmed' through yet another laparoscopy. She found herself in the a-diagnostic category with an incidental diagnosis doing nothing to transfer her to the status of the 'diagnosed patient'.

The incidental diagnosis of endometriosis did not mean immediate inclusion in the diagnostic category of endometriosis. The incidental diagnosis neither explained associated symptoms nor led to immediate treatment. In this case, it is possible that the 'incidental diagnosis' lacked urgency because the patient did not have a long antecedent history of severe pain and heavy bleeding that could be directly linked to the endometrial foci that were visualized on laparoscopy. Indeed, Rachel stated that she had never experienced problems with periods until she was in her early thirties. The dermoid cyst had to be eliminated so that the terrain could be cleared for the endometriosis disorder to emerge. It is then that the patient's complaints could be

linked to the diagnosis with subsequent formulation of the treatment protocol and gradual emergence from the a-diagnostic group.

C. Self-Diagnosis

When women described going to the doctor with a 'self-diagnosis' of endometriosis, they were in fact describing an attempt to escape the a-diagnostic category by bringing the suggested diagnosis to the attention of their medical providers. This required significant effort and work. The women researched the term endometriosis and various aspects of the condition and learned something new about the word 'endometriosis'. Despite this increased knowledge, they still described not being believed. For example, Valerie explained:

> *If I hadn't read about endometriosis online before my appointment, then I would not have been able to make the informed decision to have a laparoscopy (keyhole surgery), which is the "gold standard" for diagnosing endometriosis. It was a good thing I did, because as it turned out, my tubes were clear, but I had extensive Stage IV endometriosis, mostly around my bowel and stomach, with 37 adhesions counted in total. This would not have been detected in a hysterosalpingogram[6]. I must say that I was not happy that it was not explained to me further. At this stage I was almost convinced myself that I had endo, but had I not had a laparoscopy it would have meant more months of needless pain, while I hoped for the correct diagnosis*.-Q

Had she not pushed for a laparoscopy, she would have waited months longer in '*needless pain'*. While she was scheduled previously for a hysterosalpingogram[4], she acknowledged that they would not have found endometriosis through that exam. Instead, as it turned out, her fallopian tubes were clear. However, the laparoscopy provided a diagnosis of Stage IV endometriosis. It was therefore because of Valerie's effort to learn about endometriosis and her willingness to be '*pushy'* that she was able to obtain a diagnosis of endometriosis. While it is unclear exactly what Valerie meant by being pushy, she qualified this as an active effort to push doctors into exploring surgery.

[6]A hysterosalpingogram is an imaging technique 'used to see whether the fallopian tubes are patent (open) and if the inside of the uterus (uterine cavity) is normal' (ASRM 2016).

However, Molly, as a doctor herself (albeit not a gynaecologist), felt that she was taken more seriously as a result. For her, presenting with a 'working diagnosis' did not cause any problems.

> *I took a "working diagnosis" of endometriosis to my GP early in 2010 but we agreed not to refer me as I didn't want a GA [general anesthetic] for diagnosis as things weren't bad enough at that time.*-Q

In this context, it may be that a 'working diagnosis' when presented to the GP did not influence the physician to go further in confirming the diagnosis because of the patient's hesitancy concerning the anaesthesia. But serious consideration of the diagnosis seems to have been given because of the patient's medical background. I suspect, that as a medical professional, Molly may have had an easier time escaping the a-diagnostic category than others lacking her educational status. Perhaps, as a doctor, giving herself the diagnosis was somehow more legitimate. Certainly, her discussion of the diagnosis seemed to have been taken seriously.

V. Positive Effects of Diagnosis

Women discussed the diagnosis as a pivotal time in their journey with endometriosis. They spoke of diagnosis as a moment that allowed them to make sense of their experiences. There was a transformation from the uncertainty linked to the a-diagnostic category to a form of perceived certainty that came with the named label. (I use the term 'perceived certainty' as this notion of the fixed diagnosis of endometriosis is quickly questioned, a by-product of being returned to or at least the continual threat of being moved back into the a-diagnostic category.) It is the diagnosis that gives women a label for their suffering. It is through this label that they feel they can make better sense of it.

A. I Am Not Afraid of the Unknown

Having a name for the entity that was causing havoc in their bodies allowed women with endometriosis to understand the potential trajectory of the disease and generally comprehend what was going on with them. The fear they felt of this previously

unknown entity was now at least diminished. Lottie spoke of wanting to be sure that it was not 'something serious' such as cancer:

> *A visit to the clinic has Lottie looking to understand what is going on with her body. Why does she suffer from such pain? The doctor explains that we have ruled out anything sinister. She expresses relief. But still asks: what do you think is causing this pain then? The doctor explains that it is likely to be endometriosis but we can only be sure through a 'keyhole' surgery which has certain risks. We can still do it if you would feel better knowing. Yes I would. We will get you consented and through pre-op today then and add you to the list.* -F

Lottie still sought an official label despite being assured that she was not suffering from something sinister. She looked for the name of this condition. She explained to me that *'I just want to know once and for all what has been causing me such pain for so many years'*-I.

Having a diagnosis provided women with a label for the entity they needed to fight. This was seen as very positive. They felt they could now move away from their feelings of powerlessness associated with the a-diagnostic category. Instead of having no way to fight or to react against the unknown element causing such problems for their bodies and their lives, the women saw the moment of their diagnosis as the time when they were suddenly given some tools to fight. Lottie stated that the endometriosis label allowed her to know what she was suffering from and what she was fighting. She could not research her condition without having a name.

Figure 4.2 below, is of a woman facing a cheetah who appears to be roaring. The woman does not look to be afraid, but instead is standing her ground. While at first glance Figure 4.2 does not appear linked to endometriosis, the woman who posted it online stated that she would caption it: 'Woman vs Endo'. The cheetah has a name now, a label: endometriosis. It can now be confronted.

Figure 4.2
Endometriosis is visualized as a wild animal and the woman refuses to concede defeat.

Figure 4.3 shows a woman at the starting line for a race she is running against several cheetahs. The woman who posted it said that her '*unofficial caption for this pic* was *Woman vs. Endo part 2'*-O. She explained that *'when you're running a race you don't want to be in, every day is a win' #endometriosis #endochicks #endostrong*-O. Knowing what she was competing against allowed her to be stronger, to acknowledge that she was fighting endometriosis every day, and she was '#endostrong'.

Figure 4.3
The struggle is transformed into an athletic competition.

B. I Don't Feel Crazy Anymore

Not surprisingly, the most common statement concerning positive effects of diagnosis that the women mentioned was 'I don't feel crazy anymore'. This was a notion that all of my participants addressed in one way or another. Many women found that diagnosis allowed them to move from the feeling of 'It's all in Your Head' associated with the a-diagnostic category to 'there is now a cause for their suffering'. Diagnosis was a means to fight against negative experiences relating to not being believed. A diagnosis provided ammunition through which women with endometriosis were able to say that they were in fact suffering from a disease and allowed them to take on the sick role and to join a form of biosociality (Rabinow 1996). The diagnosis helped them to demand they not be judged, and that their pain be accepted as real.

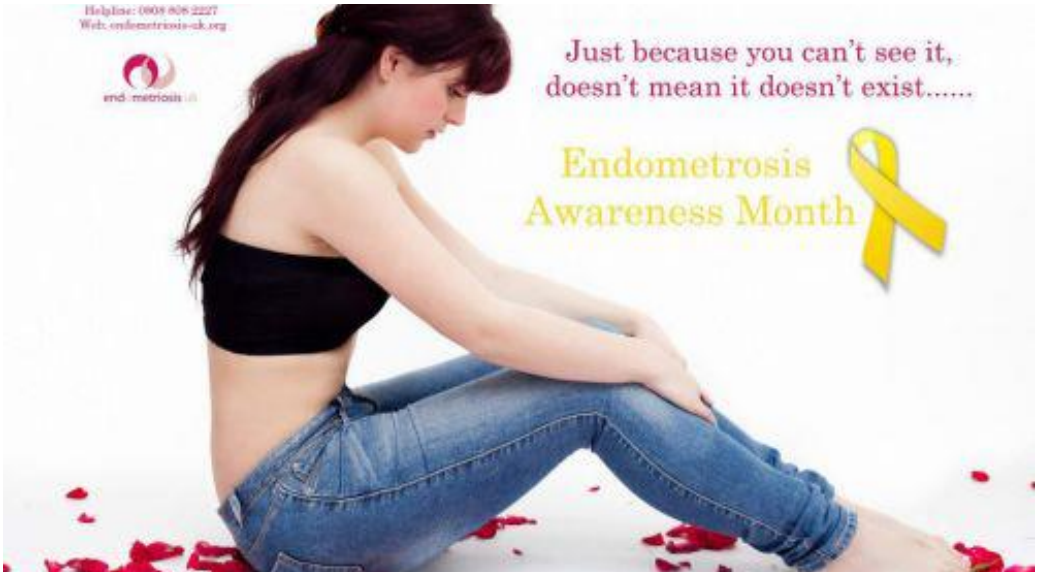


Figure 4.4
A poster for Endometriosis Awareness Month emphasizing the notion that the disease is invisible but real.

Figure 4.4 addresses this notion of the invisibility and the 'unrealness' of endometriosis and its associated symptoms. It tells us, 'Just because you don't see it, doesn't mean it doesn't exist'. The label allows women to create images linked to the endometriosis awareness movement, which ironically enough targets the a-diagnostic category and critiques the notion that endometriosis is a non-existent disease entity.

C. Resistance Through Biosociality

While I will discuss the endometriosis awareness movement further in Chapter 9, I note here that diagnosis ultimately provided women with endometriosis the tools to grapple with the disease in a group context and to become biocitizens. Membership in the group or the community of those with the disease, something that women can only receive through the label, allowed women to avoid the a-diagnostic category and the notion of the 'unrealness' of their symptoms.

Women with endometriosis so commonly felt the need to defend their symptoms as 'real' that many images online related to this topic. One woman posted the following:

Figure 4.5
A frequently posted image alluding to the invisibility of the disease and the difficulty with its diagnosis.

Figure 4.5 shows a certain level of anger. It was an image found on multiple sites and posted several times; it obviously appealed to some women with endometriosis. This anger, while linked to the idea that endometriosis is an unseen or invisible disease (please see Chapter 7 for more discussion of this), is also linked to the struggle to obtain the endometriosis label.

This notion that others do not believe that 'I am ill' or 'I am sick' (in American English) was common. It was felt that with a label came more belief in the women's experience, both by others and by themselves. Figure 4.6 states clearly 'My pain is real.' It suggests that there is no excuse for not knowing or understanding this pain. Instead, one should Google it, or simply read more about it. However, the unspoken message is

that one must have a term, a name to Google or to read about. Without a label, it is a fruitless exercise.

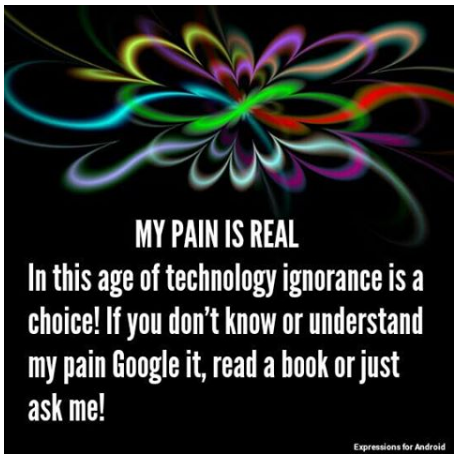


Figure 4.6
The patient's frustration and exhaustion at the problem of diagnosis.

Women with endometriosis described how the diagnosis helped to decrease their sense of isolation. They talked more with friends, family and acquaintances about their symptoms and their experiences. The label connected their complaints to an illness and moved them away from the silence towards others. Women with endometriosis also explained how the diagnosis allowed them to join support groups online or in person and to feel they were not 'alone in this'. While I will examine this in more detail in Chapter 9, this biosociality points to the endometriosis label as an effective form of admission to the group.

VI. Negative Effects of Diagnosis

While the endometriosis label stands for certain positive effects that we may typically expect from the ability to take on the 'sick role', it also brought with it a burden of responsibilities that included expectations of control over one's own body.

> *The patient is to become skilled, prudent and active, and ally of the doctor, a proto-professional – and to take their own share of the responsibility for getting themselves better* (Novas and Rose 2000: 489).

Some women in this study spoke of feeling both disappointed and sad that a diagnosis of endometriosis did not allow for feeling better, and that the diagnosis also carried a feeling that there was a responsibility to become an expert patient.

A. I Feel Sad/Disappointed

Women with endometriosis discussed the initial diagnosis of endometriosis as an experience accompanied with considerable sadness. The first feeling was a sense of depression associated with learning more about endometriosis. For example, Sandra stated:

> *I haven't been diagnosed with endo but my doctor is pretty sure that it's what's wrong with me and I'm making another appointment tomorrow so that I can go in for more definitive tests or whatever you want to call the camera thing and this sucks and I'm kinda sad so yeah.*-O

Sandra, while not yet having the official diagnosis, admitted feeling sad at the prospect of receiving it. She described both sadness and a general feeling of negativity regarding the possibility of carrying the endometriosis label. Similarly, in discussions in the support group, women spoke of the deep feeling of sadness associated with a new diagnosis of endometriosis. Lou was at a loss. She described feeling depressed and overwhelmed by new information about endometriosis. She felt powerless at having to face the steps ahead of her, including new medication choices, and the very real possibility that treatment might be unsuccessful.

Gaining the endometriosis label did not consistently translate into feeling better. Instead, some women considered their symptoms to be worse, as the treatments had many side-effects. They wished someone had told them about the possibility that the side-effects might be worse than the original symptoms. Janet pointed out that she was very disappointed when she first realized that the treatments were not working very well and in fact had such horrible side-effects that she actually felt worse on the medication. When she received the diagnosis, she had hoped that it would be the end of her nightmare; instead, in some ways it was the beginning. The realization that the treatments were largely ineffective and that the damage to her fertility had already been

done was, in her words, '*Devastating, just devastating'*-SSI. Figure 4.7 playfully approaches this notion of side-effects being so prominent and having such a strong effect on a women-with-endometriosis symptom profile. It asks in a sense why there are never any good side-effects.

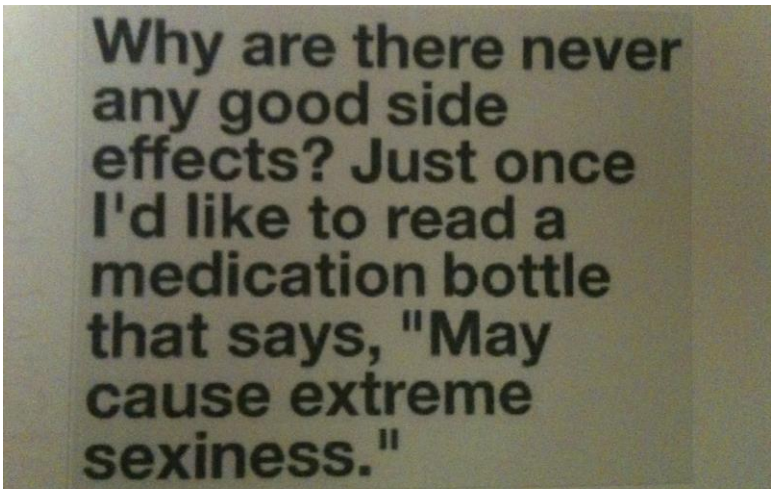


Figure 4.7
A patient laments the reality that treatment of endometriosis carries multiple inconveniences.

Women also spoke of feeling that after the diagnosis, they were left to try and sort out their own symptoms. They often reported being given a drug and told to try it for several months, without being properly forewarned about its side-effect profile. This caused them to experience increased levels of stress; they often physically felt more ill, and at the same time worried more over their inability to fulfil their roles as women.

B. Becoming the Expert Patient

Some women with endometriosis reported feeling unsure of what the term endometriosis actually meant when they first heard it. They described the necessity of researching the term initially. Their gynaecologists did not spend time truly explaining the condition, what it was, or the implications for future management. Almost all of the women I interviewed explained that '*You're just left to it*'-SSI. They were not forewarned about the upcoming struggles with the disease. Alice, for example, said that:

> *When you're diagnosed you're told you have this condition then you're kinda left to it um and unless you have access to the internet and can go about researching it yourself independently I think a lot of people would feel at a loss about what endometriosis meant. I wish we'd be given information booklets or fact sheets about it.*-SSI

In her case, little information was provided about endometriosis at the time of diagnosis. Instead, it was for the patient to take on the responsibility to educate herself, a finding echoed by Seear (2009c, 2014) who suggested women with endometriosis experienced an increase in 'women's health workload' (Seear 2009c: 199), because of time spent researching the illness.

Women with endometriosis agreed that being taken seriously, or somehow gaining some legitimacy as a patient, comes with age and with education. The beginning of the illness trajectory was associated not only with youth, but with experiences of various forms of being 'fobbed off' and feelings of 'madness' and 'paranoia', all experiences linked to the a-diagnostic category.

> *At the beginning when I was young it was just quite patronizing off well have you you know you've fallen out with your boyfriend, you having relationship problems, is there issues at home, or are you worried about things as if you've totally made it up, and you feel like you know you're going mad, and you're paranoid.*-SSI

The need to become an expert on their own condition began when they first heard the term used in relation to their own bodies. They spoke of the contrast between their previous state: not knowing and being unable to know, versus not knowing but now having a specific entity to research. The endometriosis label freed them from this state of questioning themselves and their own understandings of their pain. It did not free them from the burden of having to increase their knowledge about this disease entity.

VII. Conclusion

Women sought the endometriosis label in the hope of finding some form of solace and resolution of their struggle to escape the a-diagnostic category. They expected great things from the diagnosis, especially in the face of such negative associations with the

a-diagnostic category. Being 'fobbed off', feeling unheard, and that 'it's all in your head' remained negative experiences for the women. They felt that medical professionals wanted them to 'go away', as they were perceived as nuisances. Positioning in the a-diagnostic category was often experienced as abandonment by doctors or the medical community in the women's time of need.

Certainly, there were some positive elements to receiving the endometriosis diagnosis. But the women also reported that some negative results accompanied receipt of the label. Expectations of what the diagnosis brought, such as a cure, or at least a significant reduction in symptoms, and improvement in their quality of life, were not always met. Since so much remains unknown about the disease, the women's expectations of the medical community may have been unreasonably high. The label turned out to be a disappointment as it did not provide women with the long sought-after treatment they hoped would correspond to their new diagnosis.

Previous literature on diagnosis and endometriosis projected a view that diagnosis is the golden chalice, a positive goal where women will gain the 'sick role' which will allow them to escape the contested aspects of their condition, gain a legitimacy where their symptoms will be taken seriously, provide decreased symptoms and ultimately a fix for all their problems (Denny 2004, Cox et al 2003a, Manderson et al 2008, Pugsley and Ballard 2007, Ballard et al 2006, Johnston et al 2015, Santos et al 2012). Manderson et al (2008) and Cox et al (2003b) did acknowledge that the symptoms of pain may not be 'fixed' through a diagnosis. Both, however, maintained that the diagnostic endometriosis label would provide 'women with a powerful resolution narrative, validating their understanding and phenomenology of their own bodies' (Manderson et al 2008) and would give 'women a measure of power that they lack … when their subjugation of pain was matched by their powerlessness in relation to their attending doctor' (Manderson et al 2008). The problem, of course, is that the escape from the a-diagnostic category may only provide a temporary label, one that risks being discarded, ultimately moving the patient back into the a-diagnostic category. I describe the latter situation in the next chapter.

Only Husby et al (2003) posited potential negative aspects to the endometriosis diagnostic label. They suggested that the laparoscopy (keyhole surgery) needed for the diagnosis of endometriosis carries with it a certain risk. While some women experienced a spontaneous reduction in symptoms, others reported being diagnosed with an illness carrying an uncertain prognosis, which is a situation that could lead to depression.

Ironically, because women with endometriosis had many of the same expectations of a diagnosis of endometriosis as the researchers above, they experienced feelings of sadness, disappointment, and uncertainty when the endometriosis label did not provide the expected solutions. The promise of the endometriosis diagnosis was left largely unfulfilled, with women often not feeling any better, experiencing large side-effect profiles, or being left with the responsibility to learn everything about their condition.

I am by no means suggesting that diagnosis of endometriosis is to be avoided or increasingly delayed, as I believe that the positives outweigh the negatives women spoke of here. However, I wish to problematize the claim that 'Prompt diagnosis ensures appropriate care' (Johnston et al 2015:102) and that a diagnosis of endometriosis truly allows women to take on the 'sick role'. Unfortunately, in this case, as seen here, diagnosis did not consistently translate into decreased symptoms, better treatment or greater understanding of the condition, nor did it always keep women out the a-diagnostic category, a topic I will address in more detail in the next chapter. The possibility of being moved into the a-diagnostic category loomed large with women feeling pressure to learn much about their condition in the hope that becoming an expert patient would help them avoid the return.

Women thus sought one label as an attempt to escape the a-diagnostic category. They wished to resist the multiple enactments at play in the clinic and to find a diagnosis that might help them adjust to their diseased bodies (Mol 2002). The goal was not only to attain the endometriosis label, but to keep it. This next chapter therefore examines the

enactment of endometriosis in the gynaecology clinic, how gynaecologists limit who can gain access to the label and thereby escape the a-diagnostic category.

CHAPTER 5

Enacting Endometriosis in the Gynaecology Clinic

I. Introduction

I walk down the corridor to outpatient clinics. There is no specific sign for gynaecology, as the clinics alternate every half-day: mornings, gynaecology; afternoons, rheumatology or urology, for example. I go in, past the receptionist, with my hospital badge identifying me as a researcher, but at the same time naming me as Dr. Griffith. I walk down the hall making the first right to clinic room 4 where the nurse has set up her station. She has the patients' files prepared on the patient bed by appointment time. When she sees a file she thinks is relevant to my research, she lets me know and she encourages the doctors, especially the registrars in the clinic, to do the same. However, she remains perplexed about my research and which patients may be included in the study. She asks,'Are you looking for patients with a pre-existing diagnosis of endometriosis or patients who may have endometriosis but are not yet diagnosed'?-F

My introduction of this research project remained confusing. Somehow, there was not enough clarity for the medical professionals working in the clinic. My usual introduction *('Hello, I am here to conduct research on doctor-patient relationships around endometriosis. So if you have any patients with endometriosis, please do let me know.')* left uncertainty about which patients and which endometriosis I was targeting. While this appeared to be a relatively simple request, in fact it was not. Both nurses and gynaecologists appeared to be confused. 'Which patients qualified?' They posed questions such as: *'Are you looking for patients with a pre-existing diagnosis of endometriosis or patients who may have endometriosis'?*-F The worry was very clear. Suppose I had included patients in my study who did not have endometriosis but something else? After all, *'undiagnosed chronic pelvic pain is not endometriosis until it is diagnosed as endometriosis'*-F. Nurses and gynaecologists also wanted to know if I was interested in speaking only to patients with current complaints. *'Do you only want to see patients who are here with complaints relating to their endometriosis'?*-F The implication was that if they no longer had complaints, perhaps they also no longer had endometriosis.

The head gynaecologist, Mr. Xavier, focussed on yet another set of questions: *'but which endometriosis do you mean?'* He explained that endometriosis patients 'are a heterogeneous group'-I. For him, when you use the label endometriosis, you may well be referring to multiple entities. Within the clinic, endometriosis was not consistently seen as one entity, but was rather a term fraught with different meanings.

Gynaecologists understand endometriosis in a variety of ways, feeling the need to separate out different conceptualizations of the disease. These differentiated forms of the disorder are distributed so that 'pragmatics dominate' (Mol 2002: 102). Mol (2002) described the distribution of enactments of atherosclerosis being separated largely across sub-specialties such as cardiology (for an arterial block), primary care (for concerns around cholesterol) or pathology (for viewing of the atherosclerotic plaque under the microscope), but still being split along 'pragmatic' (Mol 2002) lines such that appropriate treatment could be provided. In the case of endometriosis, the enactments do not usually inhabit different locations and subspecialties within the hospital but are concentrated within gynaecology. Thus, the gynaecologist bears the burden of dealing with and characterising the various enactments of endometriosis.

Gynaecologists make use of the multiplicity of endometriosis and distribute its enactments, as this allows them to envisage or choose a treatment protocol that would be appropriate for the patient. Collapsing the different forms of endometriosis in a single entity does not allow for clear treatment goals. It is important to keep in mind, as Mol (2002) suggests, that one basic reality related to the concept of accentuating multiple enactments of any diagnosis is that care should be improved.

Endometriosis does not follow a typical diagnostic trajectory but instead the pathway moves in and out of the a-diagnostic category, leaving a label that is significantly contested. The fluidity of the diagnostic pathway stems from the multiplicity of endometriosis. Because endometriosis is still linked to the uterus and gynaecology, the endometriosis label, suggested treatments, and associated 'lay-professional' epidemiology remain linked to understandings of womanhood. This 'lay-professional'

epidemiology, a notion I have adapted from Davison et al's (1991) notion of 'lay epidemiology', the way in which lay people understand the epidemiology of a condition, notably differs from the public health epidemiology of endometriosis that is outlined in clinical guidelines, for example.

The use of the term endometriosis in the gynaecology clinic is unclear and potentially confusing. Gynaecologists both associate endometriosis as multiple things (and of course do not always agree on its enactments), and use this complexity to limit their application of the diagnosis. So while the gynaecologists in this study acknowledge multiplicity of the disease, they also engage in efforts to reduce multiplicities in order to facilitate use of the diagnostic term and enhance treatment planning, with diagnosis only coming after 'treatment' or at least laparoscopy. The gynaecologists conclude that endometriosis remains a contested term, where the multiplicity of the potential meanings attached to the diagnosis undermine the validity of the diagnostic term.

The complex diagnostic categorization of endometriosis is related to: its multiplicity; its association with specific definitions of womanhood; and the unusual non-linearity of its diagnostic trajectory. In this chapter, I examine the multiple ways endometriosis is enacted in the clinic, the fluidity of the endometriosis label, and the way in which the label becomes limited by its association with 'womanhood'.

II. Pragmatics Dominate: The Multiple Enactments of Endometriosis

> *You may find that these patients are a heterogeneous bunch, both symptoms, pain level and psychology as well as age as some are older and some younger. The problem may be trying to put the same label of endometriosis on all of them*.-I (Mr. Xavier – Consultant Gynaecologist)

The heterogeneous characteristics that Mr. Xavier mentions here confirms his feelings that there are multiple endometrioses. This multiplicity is based on his experience with

the physicalities of the disease. For him, endometriosis patients should not be considered as one category but could be sub-divided into groups according to pain levels, age, symptoms and something he referred to as 'psychology'. Such separation of 'endometriosis patients' into subgroups implies an understanding of endometriosis as not one category, but rather as imbued with a certain multiplicity. The self-evident problem is that the subgroups are still being labelled with the one singular label: endometriosis. Like his fellow consultants, he felt clear that endometriosis and therefore the endometriosis patient is not one unified notion but rather several entities with the same label. These multiple enactments of endometriosis live in the same space, the gynaecology clinic, but remain separate in that they are not included in the same clinical interaction. The gynaecologists here distribute the enactments of endometriosis such that they do not interact or otherwise clash. Separating out these different enactments of endometriosis allows the gynaecologists to prioritize certain treatment protocols over others and place value judgements on what the goal of that clinical interaction should be.

While gynaecologists appeared to agree that there were subdivisions in patients with endometriosis, they did not necessarily agree on the subcategories. The three main categories of endometriosis patients were based on: presenting symptomatology and the resulting treatment modality; the visual aspects of endometriosis as large cystic lesions or microscopic, ectopic, endometrial lesions; and the projected clinical outcome. These three categories corresponded respectively to aspects of the physician's work: eliciting the patient's presenting complaints and constructing of the treatment plan; visualising aspects of endometriosis lesions determined through macroscopic and microscopic examinations; and the experience of feeling more or less able to heal the patient.

A. Enactments Based on Presenting Symptomatology

The categorisation of patients on the basis of symptomatology was reflected in the comments of the gynaecologists who asked me whether I meant '*endometriosis causing pain, causing infertility or causing dyspareunia'*-F. Although all patients suffered from endometriosis their complaints about the disease catalysed a form of differentiation into

categories. Some patients who were more concerned about their fertility. Others were solely interested in treatment for pain. Still others were concerned about the special pain related to sexual intercourse. The distinctions made among different categories of patients were so prominent that patients presenting with infertility as their main complaint would attend a different clinic. This infertility clinic, while not located at the same hospital, was still run by one of the consultants who worked in the clinic(s) where I did my fieldwork.

1. The Endometriosis Patient with a Mixed Picture

The concept of the mixed endometriosis patient, one with a mixed picture of presenting complaints (chronic pelvic pain, dyspareunia, and infertility) at the same time was seen in the clinic as a hypothetical. As a practical matter, patients were assigned to the treatment they required, and the likelihood of needing to treat all three at the same time was low. Patients were seen to have priorities in what they needed help with first. Of course, if a patient complained of pain during sex, you would need to treat that before potential infertility. The reason for being unable to conceive could be linked to not having sexual intercourse. In addition, dyspareunia was not a complaint women generally felt comfortable bringing up with their clinicians, a notion further explored in Chapter 7.

2. Infertility and Pelvic Pain

Women with endometriosis seeking help for infertility were not seen in the gynaecology clinic that I attended. The clinic focused on pain, and secondarily dyspareunia.
The treatment of pelvic pain with hormonal treatment meant using continuous birth control pills or GnRH agonists which put patients into pre-mature (and reversible) menopause. This means that they cannot be used in a patient looking to get pregnant. Pragmatics dominated such that these forms of endometriosis were separated and split between clinics.

Lily, for example, despite previous treatment of her pain with oral contraceptives, wanted to get pregnant. The treatment plan therefore prioritized conception over pain relief, and the hormone treatment was discontinued.

> *Clinical endometriosis – after excision plus diathermy of endometriosis and focal haemorrhage suggestive of endometriosis. Wants to get pregnant now. So off OCP.* – Medical Notes

The medical notes on the topic show how much this is just a given. It is a matter of practice reality; one objective must take precedence. Lily cannot both try to get pregnant and be given oral contraceptive pills for treatment of endometriosis. These two aims are in direct contradiction. Thus one must take precedence over the other in the immediate term. Only one enactment of endometriosis can be primary in this scenario. So much is the separation between these two enactments of endometriosis that when Abby presented to the clinic with concerns about fertility or (infertility) she was asked by Mr. Xavier to come back and see his colleague, who focussed more on infertility. The clinic for infertility was not only on another day but in a different building.

The distinct separation between these two different 'endometrioses' meant that each was taken effectively as a distinct clinical entity, with each having not only its own treatment protocol, but also its own clinic visit, and sometimes its own clinic. The distribution of enactments allowed clinical work to take place and also meant that in any one clinic visit, one clinical presentation necessarily took precedence over the others. This made treatment planning easier.

3. Dyspareunia and Pelvic Pain

It was surprising how the enactment of endometriosis relating to dyspareunia was handled. Theoretically, in terms of treatment options, dyspareunia and pelvic pain could be treated together. In the clinic, however, they were considered as one, and dyspareunia was largely dismissed and subsumed under the complaint of pelvic pain. Treatment for dyspareunia resulting from endometriosis and pelvic pain was largely the

same. In contrast to problems related to fertility which were managed elsewhere, dyspareunia and pelvic pain were kept together.

> *Jill explains that her symptoms are pelvic pain and also pain during sex – in presenting her case to the consultant gynaecologist, the registrar begins and focussed on her complaints relating to her pain. And, the plan they come up with is presented as a way to reduce her pain levels*. –F

Thus, despite Jill's speaking of both matters separately, within the clinic visit, they become one, CPP. Dyspareunia thus disappeared in practice.

In the clinic, the hierarchy among the three separate symptoms CPP, infertility and dyspareunia therefore remained unclear in that CPP was the most common symptom I saw, with few women with endometriosis complaining of dyspareunia. This was likely a result of the associated stigma (a notion I will discuss further in Chapter 7) and a feeling by women with endometriosis that it was very difficult to discuss issues related to sex with their doctors. However, women with endometriosis reported a significant hierarchy in which infertility was seen to be a more 'legitimate' complaint than pain. This meant that these women had access to surgery and to visualisation and diagnosis of endometriosis (a topic I will cover in Chapter 7).

B. Enactments Based on Visual Characteristics of Endometriosis

The separation of endometriosis patients based on the visual characteristics of their endometriosis depended on the presence of either large 'destructive cysts' or small lesions. These were considered different diseases with different disease trajectories. 'Destructive cystic endometriosis' was largely seen as more serious than the microscopic ectopic lesions of endometriosis. This differentiation in severity level appeared linked to the potential effect on fertility; microscopic implants of endometriosis were less likely to threaten fertility. Ms Kaplan, a consultant gynaecologist, explained that:

> *... lots of women with tiny spots of endometriosis can have quite mild symptoms ... and never get something different. It doesn't change; they don't suddenly have big endometriomas or anything else.*-SSI

She also explained that what makes her worried is if *'there's big cystic destructive endometriosis going on'*, as this implied potential to affect fertility later on. For her, the main concern was fertility. This notion of seriousness of symptoms linked to infertility relates to those parts of Chapter 3 where I discuss the role of women as first and foremost procreating, but also to ideas around the stigmas of childlessness, discussed further in Chapter 7. How this multiplicity ultimately played out within her clinic is unclear as I was unable to attend her fertility clinic.

C. Enactments Based on the Gynaecologist's View of the Clinical Outcome

In contrast, Mr. Xavier subdivided endometriosis patients based on his view of the failure or success with his cases. He commented:

> *There are three types of endometriosis patients:*
> 1. *Patients who have come and been: they have had surgery and feel better. They think you are wonderful because you 'fixed them'.*
> 2. *Patients who have surgery and don't feel better.*
> 3. *Patients without a diagnosis. They are very different.'*
>
> *These patients often feel we clinicians don't believe them because we can't fix the problem or there is no proof.*-I

He separated patients into those who felt better and were helped by gynaecologists and those whose doctors felt unable to help. This division implied that the clinical outcome might translate into groups of patients who were considered 'difficult' or 'wonderful'. The impact of the feelings of powerlessness that doctors experience with difficult patients will be examined in Chapter 6.

III. The Fluidity of the Endometriosis Label

I have presented the ways in which gynaecologists distinguish the different enactments of endometriosis, distributing them in ways that do not overlap. At the same time, gynaecologists limit use of the endometriosis label and its application to patients. Thus, while endometriosis is both enacted in multiplicities, it is also limited and circumscribed, with the label given and taken away in ways that belie a normal diagnostic trajectory of presentation with symptoms, diagnosis, and then treatment.

A. Means of Limiting the Application of the Endometriosis Label during Diagnosis

1. Dismissing Undiagnosed Chronic Pelvic Pain as Potential Endometriosis

Health-care professionals in the gynaecology clinic did not see longstanding chronic pelvic pain (CPP) as potential endometriosis. This occurs despite guidelines (ESHRE and NICE) suggesting that CPP is one of the main symptoms of endometriosis, and a symptom that should spark a consideration of endometriosis in the differential diagnosis[7]. This appeared to be linked to the notion that previous evaluation by medical professionals of the CPP would stand as correct. Accepting that CPP previously determined not to be endometriosis might still be endometriosis meant that the previous evaluation in some way was flawed. While CPP would normally be evaluated with several diagnoses in mind, including infections and endometriosis (Uptodate) long-standing CPP appeared to be evaluated differently. CPP was often linked to psychological or non-gynaecological origins, and thus was sometimes viewed as outside the purview of gynaecology. This presumed that gynaecological reasons for the pain had been previously ruled out.

[7] The differential diagnosis is 'the determination of which one of two or more diseases or conditions a patient is suffering from, by systematically comparing and contrasting their clinical findings' (Dorland's Illustrated Medical Dictionary 1975: 435).

In contrast, some GPs would re-refer to the gynaecology clinic when patients would have repeat complaints regarding chronic pelvic pain that needed re-evaluation. Several women were thus seen by definition as non-endometriosis patients, despite their presenting with CPP. For example, Eliza presented to the clinic with a twenty-year history of CPP,

> *I was told this is not a patient for your study. But, she has CPP yes? Yes but she doesn't have endometriosis. Honestly, that case is not worth your time. –F*

During the clinic visit, it came out that Eliza had had previous surgery in which endometriosis was not visualised, thus effectively excluding the potential for a future diagnosis of endometriosis. Instead, the gynaecologist explained that there was little to be done, and afterwards spoke of Eliza's linked psychology.

2. Questioning the Link between Positive Laparoscopic Findings and Pain

The standard for a diagnosis of endometriosis is provided through laparoscopy and subsequent visualisation of endometriosis (Redwine 2004). However, in practice, identifying endometriosis tissue on biopsy and microscopic study did not necessarily explain the cause of the patient's pain. Kathryn, for example, had visualised endometriosis in the form of an endometrioma and a pathology report confirming endometriosis. Mr. Xavier still questioned whether her pain was caused by endometriosis and wrote in her medical notes:

> *Endometrioma removed ultrasound shows normal ovaries. No significant endometriosis seen at time of surgery. If surgery and mirena [coil/IUD] not helped then is endometriosis really cause of pain? Explained zoladex is the last treatment option — if no improvement then have to think chronic pelvic pain rather than endometriosis.* –Medical Notes

The existence of pain and visualised endometriosis did not necessarily establish endometriosis as the cause of pain. For the link to be made, a patient's pain had to respond to treatment. In other words, if the patient got better with the treatment, then and only then could it be certain that her pain was the result of endometriosis and not something else.

It is not surprising that the gynaecologists were hesitant to associate pain in every case with laparoscopic findings of endometriosis. As discussed in chapter 3, endometriosis was historically defined solely by pathological findings through surgery, not by symptoms. Any symptoms were largely separate from the term endometriosis and there was a split between visualized endometriosis and symptoms. This then raises the issue of incidental findings of endometriosis. Incidental findings are previously undiagnosed medical conditions that are discovered unintentionally. Both ESHRE and NICE mention the possibility of incidental findings of endometriosis implants on pathology, despite lack of symptoms. Both sets of guidelines mention this in their definition of endometriosis, but ESHRE additionally includes 'asymptomatic endometriosis' as a separate entity. This is done both physically in the document by placing it near the end and through giving it a separate definition and treatment. The implication from ESHRE is that symptoms must be present for endometriosis to exist as a disease entity. In contrast, the NICE guidelines suggest that symptoms may not be directly linked to endometriosis found on pathology. This leaves the potential for patients' symptoms to be questioned later on even after pathological confirmation of endometriosis.

The ESHRE guidelines give the incidental findings of endometriosis a separate name: 'asymptomatic endometriosis'. This is defined as 'the incidental finding of peritoneal, ovarian or deep endometriosis without pelvic pain and/or infertility' (ESHRE 2013:76). The guidelines go on to discuss the prevalence of 'asymptomatic peritoneal endometriosis', with numbers that are quite different from the numbers for women with endometriosis. This places 'asymptomatic endometriosis' as a separate condition.

> The true prevalence of asymptomatic peritoneal endometriosis is not known, but between 3% and 45% of women undergoing laparoscopic sterilization, have

been observed to have the disease (ESHRE 2013: 76).

This distinction made between endometriosis and asymptomatic endometriosis becomes even more apparent through the recommendations for treatment of 'asymptomatic endometriosis'.

> The GDG (Guideline Development Group) recommends that clinicians should not routinely perform surgical excision and ablation for an incidental finding of asymptomatic endometriosis at the time of surgery, since the natural course of the disease is not clear (ESHRE 2013: 76).

In contrast to their recommendations on treatment of endometriosis, the GDG explains that the risks of surgical treatment especially the 'risk… of damage to the bowel, bladder, ureter and blood vessels' are not warranted given that there are no clinical trials to assess whether surgery would be of any benefit (ESHRE 2013: 76). In addition, there is limited risk of asymptomatic endometriosis becoming symptomatic. The recommendation is for clinicians to inform their patients of any incidental findings of endometriosis (ESHRE 2013).

3. Using Empirical Treatment to Diagnose Endometriosis

Empirical treatment is founded on practical experience and is not established scientifically (Stedman's Medical Dictionary 2016). Several consultant gynaecologists who advocated for treating endometriosis empirically explained that there was no need to see endometriosis on pathology, as the treatment before and after 'official' diagnosis would be the same. One consultant explained:

> *Well my starting point with women who've got pain that's typical of endometriosis would be to get a good history from them so that we can talk about [what] that means. To acknowledge that pelvic pain is not uncommon and that it is often managed symptomatically. I would examine them and take a scan but if they have effectively a normal pelvis to clinical examination* ***on*** *an ultrasound scan I wouldn't necessarily go down the route of offering them a laparoscopy for instance for confirmation. I'll tell them that we can do that and I'll do it if that's what they want if it seems appropriate. But I'm also very happy knowing that if I do a laparoscopy I might burn a couple of spots of endometriosis and that might make no difference to their symptoms what-so-ever. So you end up then still treating them exactly the same as if you hadn't done the laparoscopy in the first place. So I'm very happy if they feel comfortable with that treating them empirically first and then coming back to review it if they have on-going problems in the knowledge that lots of women*

> *with tiny spots of endometriosis can have quite mild symptoms are treated symptomatically and never get something different it doesn't change they don't suddenly have big endometriomas or anything else.*-SSI

The only difference after surgical intervention might be if there was no visualized endometriosis then *'she does not have endometriosis'*-F, thereby ruling endometriosis out. This directly contradicts ESHRE guidelines that explain that endometriosis implants may be present even though they have not been visualised.

In contrast to this advocacy for empirical treatment seen by the consultant gynaecologists, ESHRE expresses concern about potential diagnostic delay as a result of empirical treatment explaining that:

> It has to be emphasized … that prescribing oral contraceptives in adolescents with pelvic pain without a definitive diagnosis of endometriosis might contribute to the well-known delay in diagnosing the disease (ESHRE 2013: 27).

Not only does ESHRE view empirical treatment as potentially lengthening time to diagnosis, but they also worry that 'starting oral contraception in young girls because of primary dysmenorrhea could be indicative of the diagnosis of deep endometriosis in later life' (ESHRE 2013: 27).

B. Means of Revoking the Endometriosis Label

When one considers the problems related to treatment of endometriosis, the fluidity of the label becomes evident. Gynaecologists do not consider the endometriosis label as fixed or static, but instead often withdraw the label. While the label is always provided through visualisation of endometriosis upon laparoscopy (keyhole surgery), often it is taken away in situations that appear linked to notions of womanhood. We will examine three situations in which a previous label of endometriosis may be revoked: treatment failure, hysterectomy, and pregnancy.

1. Treatment Failure

In the clinic, gynaecologists commonly applied the label 'endometriosis' to their patients' pain only after treatment appeared to have had some success.

> *If we give you a GnRH-agonist and your pain gets better then we can be fairly certain that a hysterectomy will help your pain and that your pain was due to endometriosis. If, however, this treatment does not help, then it is likely that your pain is due to something else.*-F

In relation to Kathryn, Mr. Xavier explained that:

> *This is the problem – we feel for her but we can't do anything. Is it endo? If pain is no better after 3 things endo is a red herring. Treating 1. Surgically, 2. GnRH analogue 3. Mirena.- I*

The treatment of 'endometriosis' remained treatment of endometriosis only if that treatment was successful. This is in contrast with the ESHRE guidelines which explain that hormonal treatments of endometriosis may not be efficacious and that such treatments may not successfully decrease pain symptoms (ESHRE 2013). Thus, within the clinic the enactment of endometriosis is focussed on endometriosis as a 'red herring' for a non-specific entity.

The understanding of endometriosis put forth by gynaecologists underlines their views of what they see as the role of doctors. Because they must, above all else, cure their patients, any failure is interpreted as 'we must not be treating an endometriosis patient'. The biomedical imperative to provide treatment and ultimately cure comes to the forefront (Thorne 1993, Koenig 1988, Lock and Nguyen 2010). Blame is shifted from both doctors and the medical community to the patient's body that not only does not behave as expected but is now stripped of its endometriosis label in favour of something else. To accept that the treatment does not work because it is just not effective would mean accepting both personal failure as a doctor and the inadequacy of a medical system that has yet to learn enough about endometriosis to treat the disease effectively.

2. The Role of Hysterectomy

In the clinic, hysterectomy remained an important treatment modality for endometriosis. Removal of the uterus symbolized the setting in which the fragmentation around this working definition of endometriosis played out. Hysterectomy was both the moment when one proved the existence of endometriosis and the time when the patient lost the label. Mr Laurie explained:

> *A hysterectomy should help endometriosis related pain. The problem is that it is difficult to be sure that the patients we see have pain due to endometriosis and not something else. We risk treating them with something extreme and it [sic] not working as the pain was due to another cause.*-I

No matter whether the hysterectomy did or did not reduce symptoms, after a hysterectomy, the endometriosis label was lost. If symptoms improved the patient was considered to be cured.

> *It is a clinic day. One of the registrars comes up to me. She asks so I have a patient who has come today presenting with something entirely different, but it looks like she had a past history of endometriosis 20 years ago or so. Would she fit your study criteria as she doesn't have endometriosis anymore?* -F

After further questioning, the registrar explained that the patient had a hysterectomy twenty years before. Since then, the patient had presented no symptoms. Consequently, the patient no longer had endometriosis. This patient, whom I interviewed later, herself stated very clearly that:

> *'Well, I don't have endometriosis anymore'*.-SSI

However, if on the other hand the hysterectomy did not reduce the pain symptoms, the cause of that pain would be shifted from endometriosis to an unknown entity. In this way, that patient no longer had endometriosis.

When a woman has a hysterectomy, she enters a realm where ahe may or may not have endometriosis anymore. This liminality becomes one where the definition of the disease is determined solely by the patient's symptoms. After a hysterectomy she is moved to a different category. This concept of hysterectomy as giving someone a retrospective 'real' label differs from what women with endometriosis firmly believe:

having endometriosis means having seen endometriosis through biopsy and pathology. In contrast, the ESHRE guidelines suggest that:

> … clinicians consider hysterectomy with removal of the ovaries and all visible endometriosis lesions, in women who have completed their family and failed to respond to more conservative treatments. Women should be informed that hysterectomy will not necessarily cure the symptoms or the disease (ESHRE 2013: 45).

While a hysterectomy may help with symptoms of endometriosis, it may not be a cure, as symptoms or disease sometimes remain present. However, according to the gynaecologists with whom I worked, pain after hysterectomy cannot be caused by endometriosis.

C. Lay-Professional Epidemiology

We will now turn to look at the 'lay-professional' epidemiology of endometriosis. Gynaecologists used their unique lay narrative of endometriosis. For them the 'endometriosis patient' is limited to a specific womanhood limited by age, education, socioeconomic status, fulfilment of social roles such as seeking fertility and motherhood. This results in their own unofficial 'lay-professional' epidemiology of the disease which is often contradicted by existing guidelines. In addition, the public health epidemiology of endometriosis remains contested with differences between the NICE (2014) and ESHRE (2013) guidelines. While ESHRE considers endometriosis a disease of women of all ages, NICE limits endometriosis to age 26 and above and women who are still menstruating. Gynaecologists, on the other hand, see the epidemiology of endometriosis as not only limited by age, but also by class and by life-course (to include only those who seek to have a family). Thus the endometriosis label is given or removed based on considerations of this 'lay-professional' epidemiology with the label attributed only to those considered truly 'women'.

The separation that Mr. Xavier suggests based on age, which I examined at the beginning of the chapter, has to do with the view that teenagers cannot have endometriosis. Women who had already gone through menopause were also seen as not having endometriosis. How endometriosis patients are provided treatment depends on

age, in that whether fertility becomes important depends largely on whether the woman is ready to try for children. This was connected to a specific age. Young women were seen as too young to have children, and women above 35 were already seen as too old.

1. Teenagers and Endometriosis

While not an official policy, within the clinic endometriosis was not considered a possible diagnosis in teenagers. It appeared as if the words endometriosis and teenager were mutually exclusive.

> *'She is not for you'* – the nurse said.
>
> *A young woman aged 13-14 with a Hijab walked past the nurses' station to many looks and comments of 'oh here we go again'. The nurse tells the doctor she has put her in room 1. A look passes between them with accompanied sighs. 'Right this one will take time.'*
>
> *She came into the clinic with symptoms of severe pain during her period so much so that she found it necessary to either not go to school or was routinely sent home by the school nurse. This was not her first visit to the clinic, it was from what I could gather the second or even third visit. 'She comes complaining of the same list of complaints every time' the nurse explained with a sigh.*
> -F

The doctors did not mention her to me at all, instead keeping me at arms length as much as possible. It was made clear to me that there was no possibility that she had endometriosis. She was considered a difficult patient but not an endometriosis one. The nurses told me that she was not ill but was just trying to get out of going to school. When I asked: '*Does she not go to school the rest of the month"*? They answered: '*she always attends'*-F. I was quite shocked by this case. Despite her clinical presentation appearing to point to a possible endometriosis diagnosis, the clinic staff continued to insist that she was not ill at all, but instead looking for attention.

In the clinic, teenagers presenting with symptoms consistent with endometriosis were not considered to have endometriosis. Instead, these women were attributed a status of difficult complainers trying to get out of doing things. This idea that the endometriosis label could only be attributed once the patient was no longer a teenager was common.

Several women with endometriosis I interviewed recounted similar stories of being told in their early teens *'oh it's her age it'll settle down* or *–it's fine, go with it, You're a woman suck it up'*-SSI. In fact, when asked when they were diagnosed, all the women I spoke with only received a diagnosis of endometriosis in their late twenties (from the age of 26 onwards).

As we shall see in the following chapter, many young women were told that teenage endometriosis did not exist and that they were 'looking for attention'. This was such an important topic that in response to a question about what doctors needed to know about endometriosis, Mary explained:

> *GPs and other health professionals need to be aware that endometriosis can affect very young girls. There are girls who suffer from endometriosis pain from the age of nine when they have their first period. Too often this severe pain is put down to 'normal period cramps' or worse 'trying to get attention'. That is completely unacceptable. Women and girls know what i[s] 'normal' for them and being in severe pain is not.*-Q

Teenage endometriosis is an illustration of the struggle to receive a diagnosis of endometriosis and to escape from the stigma linked to menstruation and the concept of menstruation as intrinsically painful. Gynaecologists' and nurses' dismissal of young women's symptoms as 'complaining' or as 'normal' placed endometriosis as solely a condition of women in their late 20s or older. In addition, it reinforced the notion around pain during menstruation as being normal and contributed to the confusion between 'normal periods', dysmenorrhoea, and endometriosis. Such notions parallel what I presented in the previous chapter on historical notions of menstruation as being by definition painful.

ESHRE speaks of adolescent symptoms of endometriosis and of normalization of symptoms of endometriosis especially in adolescents as a cause of delayed diagnosis. NICE does not recognize this as an issue and states that: 'Endometriosis is most commonly diagnosed in women between 30 and 40 years of age, and is uncommon in those younger than 20 years of age' (NICE 2014). In addition, on another page, NICE suggests that endometriosis should be looked for 'from 16 years onwards' (NICE 2014)

potentially leaving out young women who may have symptoms of endometriosis when they first menstruate, which can be as early as age nine (NICE 2014).

The view of teenagers as being unable to have endometriosis suggests an understanding of women's gynaecological careers as limited to beginning only in their mid-to-late twenties. Teenagers appear to not yet be considered women or at least fully women. With teenage menstruation considered in some way to have an alternative quality to that of 'women', and somehow not yet truly menstruation, this suggests that teenagers are seen as unable to have a problem with their gynaecological organs. Gynaecologic organs are apparently not 'fully formed', and not yet in complete working order. As a result, they are not yet able to be 'faulty' and linked to illness. Thus, the gynaecological career of women may start in their twenties, an age at which it may also be considered acceptable to start a family.

Teenage pregnancy was not something that doctors felt would help symptoms of endometriosis. While pregnancy as treatment was reported by women with endometriosis as a suggestion from their doctors, it was usually a suggestion made after the original visualisation of endometriosis tissue. Thus, few if any spoke of such suggestions being made in their teenage years. Consequently, teenagers were not seen to have endometriosis. Neither were they offered suggestions for treatment that including pregnancy.

2. Endometriosis and Menopause

As seen in the section on 'Hysterectomy as Cure' above, the gynaecologists in this study did not believe that endometriosis can occur in women who have gone through menopause. For them, not unlike their view of teenagers and endometriosis, endometriosis and post-menopause were mutually exclusive terms. These older patients could either have endometriosis or be in menopause. This notion contradicts ESHRE's view that endometriosis may be reactivated in post-menopausal women, recommending that:

> … in postmenopausal women after hysterectomy and with a history of

> endometriosis, clinicians should avoid unopposed estrogen treatment. However, the theoretical benefit of avoiding disease reactivation and malignant transformation of residual disease should be balanced against the increased systemic risks associated with combined estrogen/progestagen or tibolone (ESHRE 2013: 75).

This idea parallels previous literature on womanhood as linked to child-bearing capabilities (Greer 1972, Scheper-Hughes 1979). Post-menopausal women were not seen as having the potential to have endometriosis, and therefore were not considered to be women, a notion that Germaine Greer previously put forth (Greer 1972).

3. Endometriosis: The 'Career Woman's' Disease

Endometriosis remains the 'career woman's' disease for two reasons. Gynaecologists speak of pregnancy as a possible cure or even a possible preventive measure (NICE 2016, 2014), with comments such as 'have you considered having a baby to help with your pain', commonly reported by women with endometriosis. This parallels quite strikingly Meigs' statements (1953) that linked women's education and careers with endometriosis. At that time, it was thought that energy taken away from reproduction was a possible cause of endometriosis. That rhetoric still stands. Whelan (2009) found that articles published as late as 2000 argued that symptoms of endometriosis were a result of a woman's 'choice to become a 'career woman' or to 'delay' childbearing, choices for which the female body … is not well suited' (Whelan 2009: 1490). Women in my study were told that a cure for their symptoms was within reach: '*just have a baby'* –SSI. As we have yet to move away from the dichotomy of career women versus family women, endometriosis may still be considered the career women's disease.

In addition, endometriosis becomes a disease of professional women because these are the women who are attributed an organic cause to their symptoms. In contrast, women whose symptoms continue to be linked to 'psychology,' and women of lower socio-economic status, continue to have a contested diagnosis of endometriosis. They were not truly considered by gynaecologists to have endometriosis. Only those women whose

symptoms were attributed to endometriosis as an organic cause, professional women, truly had endometriosis.

4. 'Psychology' Linked to Socioeconomic Status

It was common to hear consultant gynaecologists explain that there was a specific 'psychology' attached to endometriosis. It was something they clearly felt uncomfortable about, only speaking of this 'psychology' in hushed tones and specifically linking it to women who have many other struggles in life, such as difficult neighbourhoods to live in and limited financial resources. Ms Kaplan explained:

> *So I think there's a psychology attached to [endometriosis] as well which fits with this sort of pelvic pain scenario where people always want to have a diagnosis and they want to have treatment that's targeted to a diagnosis but actually you don't always need to have that in order to make it OK. ...*
>
> *And I think there are some women that's the sort of self-fulfilling thing you meet in the clinic and they say yeah I saw doctors for years and then I finally had this diagnosis of endometriosis when you look back they had two spots of endometriosis somewhere but then suddenly this is the whole story and you know it goes on forever and they've got into this horrid cycle of psychology and pain and things which is very difficult to break.*-SSI

The link between a diagnosis, a label, and the a-diagnostic category becomes inescapable. When the label is attached to the patient, the cause of the pain is directly linked to the endometriosis implants. However, when this link between implants and pain is questioned, the label itself is questioned and becomes no longer valid. The pain the patient experiences is then attributed to a non-specific other, to an unknown entity whose only set parameters are that it is not endometriosis. This unknown easily translates to 'a psychology'. As the endometriosis label comes and goes, so does the 'It's all in your head' psychology. For a 'true endometriosis patient', it's not all in one's head, but when the label is questioned, so too are the origins of the symptoms.

However, during my fieldwork I noted that this complicated method of applying the label of endometriosis retrospectively, appeared to be reserved for less educated patients. Educated patients seemed to be given the endometriosis label more easily. For example, Denise, a pharmacist at a nearby hospital was investigated for possible

fibromyalgia. She was quickly given the endometriosis label with the doctor writing 'I wondered if her symptoms might be consistent with endometriosis'. For educated patients, if the treatment did not work, the interpretation was more likely to be that the treatment was simply not effective. The pain these patients experienced was more likely to be considered organic. So even if there was a thought that the pain might result from something other than endometriosis, this cause was usually clearly indicated and was something that was either going to be or currently was being investigated.

This remains in sharp contrast to the covert undertones that consultant gynaecologists use when speaking of the 'psychology of some endometriosis/chronic pelvic pain patients.' The 'specific psychology' somehow is connected to the patient experience of chronic pelvic pain. On the one hand it is clearly linked by these doctors to patients of lower socioeconomic class; on the other it is linked to a cause, albeit not one clearly stated for fear of being somehow impolite or inconsiderate of these patients' pain. Interestingly, this 'psychology' seems to be absent from patients of higher socioeconomic status.

IV. Limiting the Enactment of Endometriosis to a Gynaecological Context

The multiple enactments of endometriosis tend to highlight the uncertainties surrounding the disease. The label shows itself to be so contested that both gynaecologists and clinical guidelines enact endometriosis in a specific, limited way, so as to facilitate clinical work. Endometriosis in the gynaecology clinic necessitates a presupposition of a specific point of view about the illness, that endometriosis is a disease of women and of womanhood. Endometriosis is seen most commonly as a gynaecological condition despite suggestions that endometriosis could be considered a rheumatological condition, and has been found to affect the entire body with the exception of the liver (Bulun et al 2005, Bulun 2009).

However, none of the gynaecologists in my study questioned whether endometriosis was in fact a gynaecological condition, linking endometriosis with hormonal treatments, the uterus, and women. While registrar gynaecologists appeared less aware of the controversies surrounding endometriosis and therefore did not mention these matters, their consultant counterparts knew of the controversies but had adopted a view that in large part fit with their treatment protocols. Thus the gynaecologists appeared to fit endometriosis into a 'definition' that conforms to a limited biomedical understanding of endometriosis as gynaecological, a view directly linked to their specific biomedical reference point. It was accepted that it was a disease to be treated under their remit.

The only exceptions to this were in complicated surgical cases involving the bowel or the urinary tract, where they felt that they might require additional surgical expertise from other subspecialties. However, even this did not classify endometriosis as a non-gynaecological disease, with gynaecologists still being the primary surgeon in such cases. For example, Mr. Xavier was waiting to hear back from the gastroenterologist to schedule the date of a surgery that they would both be available for due to possible involvement of the bowel by endometriosis. While he acknowledged the potential involvement of other organs, he still considered endometriosis to be primarily a gynaecologic disease with expectations that hormones would help endometriosis. At the same time he viewed it as a disease of women – often saying 'women with endometriosis', considering endometriosis to be a disease affecting only women and therefore gynaecologic.

A. Defining Endometriosis only through Gynaecology

The definition of endometriosis links endometriosis to both the uterus and hormones, and more generally gynaecology. (This is true of both gynaecologists' understanding of its definition and guidelines.) While the approach to endometriosis by the gynaecologists in the clinic differed remarkably based on the training of the doctor, with registrars (especially earlier in their training) having a very different and much less complex understanding of endometriosis than their consultant counterparts, both groups viewed endometriosis as a gynaecological condition.

All the consultants I interviewed began by describing endometriosis as a gynaecological condition, their endometriosis patients as women, and the disease as the displacement of endometrial-related tissue outside the uterine cavity. Focus on such a definition of endometriosis directly linked endometriosis to the uterus and its lining, thus contributing to the notion of endometriosis as a gynaecologic condition.

The view that endometriosis is by definition a gynaecological condition is supported by the NICE guidelines as well as the ESHRE guidelines. Both ESHRE and NICE define endometriosis:

> Endometriosis is defined as the presence of endometrial-like tissue outside the uterus, which induces a chronic, inflammatory reaction (ESHRE 2013: 5).
>
> or
>
> Endometriosis is the presence of tissue resembling endometrial glands and stroma outside the uterine cavity, which induces a chronic inflammatory reaction (NICE 2014: 3).

Both definitions emphasize that the endometriosis implants are in fact biologically different from endometrial tissue within the uterus. In addition, both discuss the inflammation associated with endometriosis, while maintaining a firm gynaecological link to the hormone oestrogen. NICE states that:

> Ectopic endometrial tissue is oestrogen-dependent and responds to the hormonal changes of the menstrual cycle, with subsequent bleeding, inflammation, and pain. If the ovaries are affected, endometriotic ovarian cysts (endometriomas) containing blood and endometriosis-like tissue may develop, which may rupture (NICE 2014: 3).

By classifying endometriosis as an oestrogen-dependent illness, neither ESHRE nor NICE begins to grapple with the contested pathophysiology of endometriosis. ESHRE does not even include a section on the pathophysiology of endometriosis in its guidelines. In addition, ESHRE does not consider rare symptoms of endometriosis, such as headaches or coughing up blood, documented in past literature (Redwine 2004).

The literature on the potential causes of endometriosis had no impact on either the guidelines or the gynaecologists here. So this divide between the older theories about endometriosis pathogenesis and the newer ideas that move away from gynaecologic causes (including notions of endometriosis as a potential rheumatological condition linked to inflammation) does not impact the rhetoric or practice related to endometriosis. This leaves us with a social construction of endometriosis linked to gynaecology despite its contested pathophysiology and multiple locations within the body.

The medical professionals from the pain clinic included a nurse, psychologists and consultants (see methodology section). While the consultants considered themselves to have a good understanding of endometriosis, the other medical professionals admitted to knowing very little about the biomedicine of endometriosis. However, members of the clinic as a whole agreed that endometriosis could be treated as a chronic pain condition (for women with endometriosis whose complaint was pain) and followed certain key principles for management of such patients. The medical professionals in the pain clinic placed endometriosis firmly within the realm of a pain syndrome and not a gynaecological condition. Thus, they acknowledged patients' experiences of being dismissed, as well as patients' grief.

B. Minimizing non-Gynaecological Symptoms

Symptoms of endometriosis still remain contested both in guidelines and in descriptions by clinicians. For the gynaecologists I spoke to, symptoms of endometriosis included: pelvic pain, infertility, and dyspareunia. Other symptoms that could be attributed to endometriosis such as nausea, episodic diarrhoea, or dysuria were likely to be thought as not linked to endometriosis. Many registrars did not seem aware of the many possible ways endometriosis could present. Instead these other symptoms only fed into the idea of endometriosis as a 'red herring' that Mr. Xavier spoke of with dysuria being linked to urinary tract conditions and nausea, and episodic diarrhoea being linked to gastrointestinal diseases. Thus women who presented with such symptoms were often asked: 'has your GP sent you to the urologist or the gastroenterologist?' Such

symptoms were often disregarded in registrars' presentations of symptoms to the consultant.

Symptoms that could be associated with endometriosis were not always attributed to the disease process, and their presence did not conclusively give someone an endometriosis diagnosis. Gynaecologists believed that these symptoms might very well be caused by other disorders even if these entities remained unnamed. In my fieldwork, gynaecologists' understandings of endometriosis complaints focussed on symptomatology linked to the pelvic region. Any symptoms potentially linked to other organ systems were not, in their minds, linked to endometriosis. This created two potential issues: women with certain symptoms struggled to access the endometriosis label and endometriosis remained circumscribed as a solely gynaecologic condition potentially leaving out non-hormonal treatments of endometriosis (see below).

This uncertainty around the symptoms of endometriosis reveals itself within the guidelines. Not only has ESHRE stated that: 'Systematic assessment of all endometriosis symptoms preferably in a prospective study setting, is yet to be done' (ESHRE: 10), the symptoms listed by ESHRE are not the same as those listed by NICE. While ESHRE lists bloating and fatigue, along with dysmenorrhoea, chronic pelvic pain, deep dyspareunia, cyclical intestinal complaints and infertility, NICE mentions none of these symptoms and focusses instead on symptoms of endometriosis as cyclical in nature. Yet for ESHRE, 'fatigue/weariness continue[s] to be [one of] the leading symptoms of endometriosis' (ESHRE 2013: 10). Gynaecologists shared the NICE view that dissociated fatigue or bloating from endometriosis despite their appearance in the ESHRE guidelines.

C. Holding on to Historical Treatment

Treatments linked to hormonal notions of endometriosis not only leave historical understandings of the disease in the foreground, but also categorizes endometriosis primarily as a gynaecological condition. This reinforces historical concepts of pregnancy and hysterectomy as cures over more recent ideas of endometriosis as

potentially a rheumatologic condition. Gynaecologists' understandings of endometriosis remain rooted in historical understandings of endometriosis as linked to women's role in society. There is also a connection to Meigs' (1953) understanding of pregnancy as cure, for example, but also to the difficulty in differentiating between normal and abnormal periods, dysmenorrhoea, and endometriosis. The 'professional' epidemiology of endometriosis differs from the 'public health' epidemiology itself contested and seen in medical textbooks and clinical guidelines.

In contrast to the treatments mentioned previously, pregnancy-improved symptoms did not determine whether a patient was considered to have endometriosis. Gynaecologists were clear that pregnancy might contribute to an improvement of symptoms, but had no expectation that pregnancy must or should cure endometriosis. This was a common suggestion given to patients in the clinic as well as other women with endometriosis. For example, a consultant told Nancy *'If you are interested in having a child, it is likely to help your pain'*-F. Within the clinic, this suggestion of pregnancy as cure appeared to be focussed on less educated patients. Patients with professional careers were not expected to become pregnant in the same way as other women.

The suggestion that pregnancy would be likely to fix the problem placed women with endometriosis into a specific role of women defined by the doctors (Seear 2009b and Whelan 1997). However, this was even more nuanced, as the role of women was considered to be different, depending on socioeconomic status. Women with higher socio-economic class were attributed the role of professional or career women or were at least allowed to choose. In contrast, women of lower socioeconomic backgrounds were assigned a role as mother or potential mother.

While pregnancy remains a treatment modality used within the clinic, it is qualitatively different from other treatments suggested by gynaecologists. It is not used to qualify women as 'endometriosis' patients, and pregnancy is not utilized as a method of applying or taking away the endometriosis label. However, patients are routinely asked to attempt pregnancy as a way to improve their symptoms. This remains a suggestion

even if patients are not planning to have children or are not in a sexual relationship at that point in time. Kathy explained that:

> *There seems to be very little knowledge about 'endo' even amongst gynaecologists. Mine repeatedly tells me to get pregnant (I'm not even in a relationship!) as that'll 'cure' it!*-Q

While ESHRE does not specifically address the notion of pregnancy as a cure for endometriosis, the guideline scope for NICE's new endometriosis guidelines published in 2017 suggest a resurgence of Meigs' 1953 notion of a possible causality between delayed childbearing and endometriosis. It states: 'Delaying childbearing, either by choice or because of subfertility, may be a risk factor for endometriosis' (NICE Guideline scope 2016: 6).

Endometriosis and womanhood remain inextricably linked. The 'true endometriosis patient' is one who is in her mid-twenties to mid-forties, still menstruating with her uterus intact, educated, with previously visualised endometriosis, and with hormonal treatments working for her. This limits very distinctly who can have endometriosis with clear connections to womanhood with, for example, teenagers, women having gone through menopause or hysterectomy not being considered potential candidates for endometriosis and therefore not truly women anymore. This parallels much previous literature on notions of womanhood as limited by anything from age to race to ability to reproduce, to the presence of a uterus and ovary. Germaine Greer (1972) wrote her seminal text, *the Female Eunuch*, on matters related to menopause and societal understandings of women who are no longer reproductively viable beings. Such notions may also be applied to race matters with relation to the large feminist literature on notions of womanhood as being limited to white women. However, my study was conducted in a region where the population was 92% White British (The Guardian 2018).

V. The Collapse of the Endometriosis Label

The gynaecology consultants generally felt that a diagnosis was not necessary for their treatment of patients. However, they did acknowledge that patients appreciated having

a name for their suffering. This did not translate into feeling that seeking a diagnosis on a patient's behalf was important. They felt that the term endometriosis is itself not useful because of the varied presentations of the condition. In addition, some consultants believed that reassuring a patient about the non-seriousness of her symptoms was enough. According to one consultant:

> *Many patients just want to know that there is nothing seriously wrong like cancer and then they are happy to continue on as they are.*-SSI

In the scope of its 2017 guidelines, NICE suggests that delayed diagnosis is a problem for women with endometriosis. The language it uses, 'many women think… [or] believe' suggests that they do not consider endometriosis patients to be viable sources of information (NICE guideline scope: 7) and therefore do not consider a delayed diagnosis problematic. In contrast, ESHRE specifically focuses on the issue of diagnostic delay in its guidelines. Not only does it clearly link delay in diagnosis to sub-optimal care, but it also associates delayed diagnosis with a worsening quality of life in endometriosis patients (ESHRE 2013).

Practically, what remains are questions about the usefulness of diagnosing endometriosis and of the label itself. Gynaecologists see the label as imperfect, implying that decision-making linked to treatment is largely separate from the term endometriosis. At the same time, the use of the term endometriosis by both guidelines and gynaecologists is part of the social construction of endometriosis as a disease of women and linked to womanhood. This is problematic and places endometriosis into this set box that defines it as gynaecologic – which of course implies only affecting gynaecologic organs. While this may alienate the few men and others who do not consider themselves women with this disease, it also validates the use of hormonal treatments for endometriosis despite the lack of biomedical literature to support this.

VI. Conclusion

In this chapter, I considered how one may challenge the notion that the unitary label of endometriosis is fixed and uncontestable. I pointed out the multiple implications that physicians attach to the diagnostic category, allowing them to separate out enactments

that if left together would make treatment protocols difficult. Gynaecologists here sought to separate out different multiplicities of endometriosis to achieve treatment goals. The result was a distribution of enactments in which pragmatics dominated not unlike what Mol (2002) described in atherosclerosis.

The a-diagnostic category emerges again here due to practices within the clinic. I have emphasized the fluidity of the diagnosis since the label may be applied and also easily revoked by gynaecologists. The unitary label of endometriosis is originally given only through the visualisation of endometriosis cells outside the uterine cavity. But the diagnosis of endometriosis rarely stays with the woman, a notion that contributes to women's constant struggle for the endometriosis label.

Gynaecologists, while being highly specialized professionals, have created a unique lay narrative of endometriosis that results in their own unofficial 'lay-professional' epidemiology of the disease (which is often contradicted by existing guidelines). For them, the 'endometriosis patient' is limited to a specific womanhood limited by age, education, socioeconomic status, fulfilment of social roles such as seeking fertility and motherhood, and visualised endometriosis. The many contested notions around endometriosis and the associated multiplicities ultimately exclude many women from the endometriosis diagnostic category. They may then transition back into the a-diagnostic category and resume their search for the diagnostic label.

CHAPTER 6

Disciplinary Power in the Gynaecology Clinic

I. Introduction

In this chapter, I examine the complex interactions that take place within the gynaecology clinic and the multiple enactments of endometriosis that occur as women seek to avoid entering into the a-diagnostic category. Here the women's coping strategies and knowledge of endometriosis come up against complicated power relations in the clinic. The women work to maximize their chances of escaping the a-diagnostic category and acquire the endometriosis label. However, some of them may return to the a-diagnostic category. The power relationship among those operating within the clinic may lead women to find themselves back in the a-diagnostic category despite having obtained a previous diagnosis of endometriosis.

While the term 'power' is commonly utilized during academic debate, often when there is little agreement over its meaning, in my own research I have found certain definitions helpful. Robert Dahl (1957) defined power as the 'ability for A to get B to do something that B would not otherwise do' (Dahl in Tim Gee 2011). Others define power as one's capacity to influence others or to exert one's will over others (Charles 1994). Implicit in these two definitions is the idea that power is in play when one party works for dominance over the other.

The idea of power comes to the fore in different ways in the study of doctor-patient interactions. Power may be linked to the relationship between doctor and patient, and to the power difference that ultimately evokes the idea of paternalism. It is in this context that observers suggest one way to rectify this power difference is to empower patients and thereby reduce the traditional paternalism expressed by doctors (Strous et al 2006). This manifestation of power is regularly seen in one-on-one doctor/patient relationships.

Goodyear-Smith and Buetow (2001) identified three general sources of power in the doctor-patient relationship: legal and social authority, material wealth, and information and knowledge exchange. Doctors utilize sources of power derived from their social authority and status (often reinforced by the law), available medical resources, and their knowledge and skills. On the other hand, patients gain power through social standing

and legal rights, financial resources, and knowledge of their own conditions (Goodyear-Smith and Buetow 2001).

Lupton (1997) has suggested that the power relations inherent in the doctor-patient relationship have evolved over the last several decades. She pointed out that patients traditionally had less power in the organized medical system, while doctors exercised the most power. This, she explained, changed with patient empowerment movements giving patients increased power so as to create a new normal in which doctors share more decision-making with patients than before. For Goodyear-Smith and Buetow, this power shift towards patients 'has led at times to the disempowerment of doctors and their portrayal as adversaries needing control and surveillance' (Goodyear-Smith and Buetow 2001: 452). Interestingly, such notions all appear to assume that there is a pool of power from which to draw, thereby placing doctor and patient at odds and struggling over the reservoir of power. In addition, such notions cling to the notion of 'power' as a relationship of dominance and subordination between two parties.

I suggest that the doctor-patient interaction may in fact not be always a struggle for power between doctor and patient. Instead, the doctor-patient interaction may be conceived as shared helplessness experienced by both parties, something I return to later on in the chapter. The struggle for power does not always simply involve patients attempting to usurp the power of medical professionals or doctors taking power from their patients. In some cases, there may not even be a 'struggle for power' at all, at least not in the usual fashion of one group obtaining it from the other. Instead, there is a collusion between doctors and patients to reproduce medical dominance, with patients responding to the clinical gaze by resisting or performing within the medical encounter (Lupton 1997, Jaye et al 2006).

Much has been written about patients as subjects of disciplinary power: the patients are seen as internalizing discourses on how they should experience disease and the subsequent self-disciplinary behaviour (Foucault 1963, Sulik 2011a, Lupton 1997). From a Foucauldian viewpoint, power within the medical culture system is a

disciplinary power which provides guidelines as to how patients experience and are expected to discipline their bodies. Disciplinary power functions therefore through such strategies as observation, measurement or comparison against an established 'norm', and convincing subjects that they should behave and think in ways that are considered appropriate. Doctors have therefore been considered the linkage mechanisms through whom such disciplinary power is exerted on patients. Physicians are an important group through whom the disciplinary power passes (Lupton 1997, Foucault 1963). I point out here that both doctors and nurses may serve this linkage role through whom such disciplinary power passes. The power may also be applied to patients as well as to the medical professionals.

I add to this the notion that doctors also resist at times the disciplinary power of biomedicine. Such notions of medicine as a disciplinary power for doctors can be seen within the abundant literature on medical education as professional socialization (Becker et al 1961, Hafferty 1998, Sinclair 1997) with associated self-disciplinary behaviour and resistance. Explicitly associating this with Foucauldian notions of biopower seems relatively new (Jaye et al. 2006), and has yet to be linked to interactions within the clinic and away from 'medical education'. It is of course possible to argue that doctors and other medical professionals rarely escape from the disciplinary power exerted through continuing medical education.

For my purposes here, I would like to move away from thinking specifically about medical education, and instead consider how disciplinary power influences clinic activities and subsequent strategies of resistance or strategies to regain control (control strategies) that participants in the clinic employ. I take the idea of control strategies from notions of power and counterpower articulated by Asbring and Narvanen (2004). They explained that power and counterpower strategies were used by patients with fibromyalgia to gain control over their situation during the health care process and to influence its course during encounters with health care providers. Power strategies were employed by those with the most power, and counterpower strategies were employed as a form of resistance to those with greater power. This framework involves the notion

that doctors and patients use such strategies against each other. In addition, it requires deciding which group or person has more 'power' in any given context. So, I suggest the term 'control strategy' instead. This frees us from stereotyped preoccupations with power struggles between individuals, or power differentials and trying to determine whether something is a proactive step or a reaction against another's strategy.

Starting from notions taken from Foucault concerning disciplinary power, I suggest that the gynaecology clinic is a space in which doctors and nurses both act as mechanisms through which the practical exercise of control maneuvers are enacted. At the same time, doctors and patients may simultaneously feel constrained and powerless, limited by disciplinary power. Thus, they resort to control strategies as techniques to resist the pressure of systemic dominance. These control strategies are used by women with endometriosis mainly as a way to gain the endometriosis label and therefore a way out of the a-diagnostic category. Gynaecologists use control strategies as ways to subvert a system that pressures them to diagnose and cure every patient; at the same time, nurses may continue acting as a mechanism through which disciplinary power is exerted.

Thus, I focus here on how the different actors in the clinic (doctors, patients and nurses) utilize what I have called control strategies in the face of disciplinary power. I describe a setting in which disciplinary power is exerted on patients through both doctors and nurses, and gynaecologists and patients both experience the disciplinary power of biomedicine such that they are expected to behave in specific ways.

II. Patients' Control Strategies

Women with endometriosis spoke of powerlessness in two different ways. The first concerned feeling loss of control of one's own body (See Chapter 8 for more detail); the second was a side-effect finding oneself in the a-diagnostic category. Both feelings of powerlessness led women to use control strategies. Because women with endometriosis felt they were often dismissed by medical professionals and positioned in the a-diagnostic category, they created control strategies in which they attempted to be

believed or taken at their word. Women used control strategies before, during, and after the clinic visit.

Several of the control strategies grew out of feeling directly disempowered by previous clinic visits. Women discussed many examples of feeling not listened to by their doctors. This was not limited to their gynaecologists but also often included bad experiences with their GPs.

Women with endometriosis largely thought of the clinic as a place where they would struggle to be heard and to be taken seriously. The clinic visit became, in a sense, a battlefield, evoking Kleinman's (1988) description of the chronic pain clinic and escalating negative interactions between doctors and patients. This battlefield was one that women felt they needed to prepare for, both physically and emotionally. Women with endometriosis felt they should be '*strong*' (as several women put it) to visit medical professionals. They spoke of learning to be more forceful during clinic visits, with one woman emphasizing that '*doctors don't listen the first time*'.

A. Control Strategies Before the Clinic Visit

For women with endometriosis, the preparation for the clinic visit was multifold and included educating themselves about endometriosis and arriving prepared with specific questions.

1. Education

Women with endometriosis (online, in interviews and in support group meetings) spoke of needing to become an expert patient, and being an expert patient meant successfully taking on the medical community. Increasing one's knowledge about endometriosis allowed one to be '*heard*' by medical professionals and especially doctors. This increased knowledge was seen as a way of enhancing feelings of strength, which was necessary for the initial interaction with medical professionals. Whelan (2007) concurs, explaining that women with endometriosis look to increase their medical knowledge to have more power as they interact with the medical community.

Learning more about endometriosis, including potential treatments that might be offered, was important preparation for a clinic visit. Many women with endometriosis stated that as they grew older and more knowledgeable about the disease, they were more likely to be believed. They sought more information about endometriosis before attending a clinic visit. Sallie explained that her goal was to '*know… more than the doctors*'. '*I read quite a lot of books*'-SSI she explained.

Learning about endometriosis was largely done either through the internet, or through support groups. Women with endometriosis described the internet as an incredible source of information. Because of the age of the women, many also stated that when they were young, they were forced to search for information in their local libraries. '*[N]ow accessing information is so much easier*'-SSI was a typical comment.

Others explained that the support group meetings served as a place to gain information. It allowed them to prepare for a metaphorical battle to access care and treatments. One woman explained at a meeting that I attended: '*I feel strong now. I can face them now. I will call the [clinic] tomorrow*'-F. The clinic visit was therefore partially transformed from an interaction where patients gained information about endometriosis, into a situation where patients largely sought to be listened to and treated. Many women had already acquired considerable knowledge relating to endometriosis and some felt they knew more about endometriosis than their doctors.

2. Question List

Many women with endometriosis thought that a list of questions was an important tool to bring with them to the clinic visit. This allowed for more control over the visit itself. They found it helpful to bring a prepared list of questions. This suggested that the clinic visit represented a threatening situation, where women were so nervous that they would forget the questions they wanted to ask.

> *So I think if you're frightened and nervous when you're going to an appointment with your consultant you're all frightened of them and not*

> *being able to ask what you want and then actually know you're going there to get some answers, it's terrifying*.-SSI

The organization Endometriosis UK, the national support group through which I recruited many participants, provides a variety of different pamphlets online for its members, including several that explain how best to prepare for a visit with a gynaecologist. One called the 'Consultation Questionnaire' focuses on how to prepare, while another, 'Getting diagnosed', gives guidelines on what to do during the consultation itself.

While the pamphlet aims to ensure women with endometriosis obtain a diagnosis more easily, it also outlines specific roles that women are expected to assume. To fulfill her role as a 'patient' it is suggested that she 'need[s] to ask questions as well as listen to the doctor.' She should prepare before attending the clinic visit. Examples of this include writing down questions the night before, as well as doing research beforehand on the internet or by calling the Endometriosis help-line.

> You need to ask questions as well as listen to the doctor. It is worth writing down your questions the night before your appointment. Get everything clear in your mind, do some research on the internet or ring the Endometriosis UK helpline: 0808 808 2227 (Endometriosis UK, Getting Diagnosed 2016).

The pamphlet also provides sample questions that have been highlighted as specifically pertinent.

> Some questions you may want to ask include:
> - What do you think is causing the symptoms?
> - Will you want me to have a scan? What sort of scan and what are you looking for? Will you want me to have a laparoscopy? What are you looking for? (Please see the separate sheet in this pack for more information on laparoscopic surgery)
> - Do you think my fertility is affected?
> - How can I control my symptoms?
> - What treatments do you suggest and why?
> - Are there any other options that I need to consider?
>
> (Endometriosis UK, Getting Diagnosed 2016).

3. Documenting Physical Symptoms of Endometriosis

Many women with endometriosis felt that a major part of preparing for their clinic visit should include consistently documenting their pain and how it limited their ability to function. While there were several different ways of doing this, they concluded that this was a useful way of showing the medical professional what symptoms they had been experiencing.

One of the methods women used for documenting symptoms was a diary in which they listed when they had pain, for how long, where, and at what level. This could be included in a patient's regular diary or calendar in which she kept her other appointments, for example, or could be started as a separate booklet. The documentation of levels or location of pain varied: some women with endometriosis documented everything with words or numbers, while other women colour-coded the levels of pain. Some focused on using more biomedical terminology to express their suffering, whereas others concentrated on visual representations of their impairments in daily functioning.

Kelly explained that she documented her symptoms in order to get herself closer to a diagnosis. She *'started to keep a diary – noticed a correlation with menstruation'*-I which allowed her to suspect endometriosis and to ultimately suggest this to her doctors. Alice described preparing for a clinic visit through documenting her symptoms after her diagnosis of endometriosis. She said:

> *I do prepare yeah. Yeah Everytime I go with a list of the symptoms I've been having how long I've been getting them, the severity of them um and what I've tried to do to help uh myself and any questions about treatments upcoming and things like that (hahaha). In fact, I have a pain diary that I brought along which my consultant said has been very useful to him. I'll just show you briefly. It's like a traffic light system I use red amber and green to show what kind of a day I've been having pain-wise the red being the most severe pains. [Orange is] a mediocre day it's a little bit um it's uncomfortable enough to cause me to have my daily activities interfered with. Green is a good day when there is only mild pain a little bit of pain and red is so severe that you're laid up and can't do much at all…. And on some days on there I've got all three colours on them that's because it's either gone from bad to worse or I've just had elements a lot of surprise spasms and pain.*-I

While a symptom diary's primary purpose seemed aimed at convincing medical professionals of the veracity of one's symptoms, it also gave women a sense of how endometriosis was affecting their daily lives. This helped some women to feel more in control, although others felt depressed by the disease and less in control as a result of their symptom diary.

Endometriosis UK, in a separate eight-page document entitled the 'consultation questionnaire', emphasizes the importance of women with endometriosis documenting their symptoms. The introduction to the questionnaire states:

> This questionnaire is designed to help you prepare for your medical appointments. Fill it out and take it with you to your appointment so you can answer the doctor's questions quickly and accurately and therefore use the limited time more effectively. It may be very useful to make a copy of this questionnaire to give to your doctor. This will provide something to refer back to at future appointments, and will help you both to monitor your condition. It is important to provide your doctor with as much accurate information as possible in order to work as a team in getting a diagnosis or managing your condition (Endometriosis UK Consultation Questionnaire 2016: 1).

Here there is a focus on the women's role as patient to monitor their own symptoms. It is explained that this should reduce the duration of clinic visits, as well as improve the accuracy of the information provided to the doctor. In addition, here I note the use of the term 'team' in reference to doctors and patients. The patient is clearly placed as having a large responsibility to monitor her own symptoms while simultaneously working as a team with her doctor. This parallels the notion of self-surveillance (particularly of women) in chronic illness and in breast cancer (Sulik 2011b).

4. Visual Presentation

Women spoke in support group meetings of the necessity of going to the doctor '*looking a mess*'. This was one method by which doctors would be more inclined to believe that the woman was ill. In discussing this topic amongst themselves, women acknowledged their practice of '*putting on a mask of health*', a concept discussed in detail in Chapter 7. Janet and the other members of the support group explained that

'*because we are so used to pretending we are healthy, we forget to show our true situation; we are suffering but we turn up at the doctor's like we would to go anywhere else*'-F. They gave each other specific suggestions as to the best way to present oneself in the clinic. Some suggested a fine line between looking ill and looking depressed. They joked about showering being a '*good thing to do*'-F, while simultaneously suggesting that they not put on make-up for a clinic visit. Finally, they agreed that the goal was to be taken seriously by their doctors. This implied necessarily taking off the '*mask of health*' before attending the clinic visit. One member suggested: '*go to the doctor's looking a mess, don't wash your hair, don't put on make-up*.' Janice and Amanda further commented that '*The worst is when you go in and [the doctor] says 'you are looking well today*. *And you think "yes but I feel awful"*" –F.

B. Control Strategies During the Clinic Visit

Patients utilized control strategies, planned and unplanned, during the clinic visit. Women, on the whole, decided to bring someone with them to the visit. They also often had considered limiting the information they intended to share with medical professionals. In contrast, women employed control strategies that appeared unplanned and were linked to interpersonal interactions among themselves. These strategies were not behaviours that women spoke of or of which they were necessarily aware. Instead, they appeared to be spontaneous and manifested during the clinic visit in response to negative experiences at the time. These included walking out of the visit, limiting the information shared with the medical professional, avoiding eye contact, and providing one-word answers.

1. Planned Control Strategies

a. Writing Down Information

Women with endometriosis often spoke amongst themselves in the support group of the usefulness of '*writing things down*'-F before attending a clinic visit. They explained that this preparation was necessary, '*as you get upset and forget things*'-F. Endometriosis UK echoed this in suggesting that taking notes during the clinic visit

may be necessary to remember what was said. 'During the consultation, take notes if you can as it may be hard to remember everything' (Endometriosis UK, Getting Diagnosed 2016).

b. Bringing Someone to the Clinic

Several women felt it was helpful to bring someone with them to the clinic visit. This was a topic regularly discussed in support group meetings. They spoke of taking a relative for support; the companion was often the woman's mother or partner. This was not only a support mechanism, but also reinforced the importance of the symptoms being experienced. Audrey explained that she took her mother with her and felt it useful.

> *It's the same with GPs as well. The original GP was not very helpful again you know he'd put it down for years and years not bothering to do anything about it, and he only referred me when my mum came with me*.-I

Endometriosis UK suggests that 'You might also want to take someone with you for support.' It goes on to suggest that 'You could ask that person to write everything down so that you can concentrate on what is being said.' (Endometriosis UK, Getting Diagnosed 2016). The implication here is that the visit may be too stressful and complex for the patient to digest and recall all that transpired during the clinic visit.

c. Limiting Information Shared with Medical Professionals

Women spoke of limiting the information they shared with their medical professionals, generally citing three different reasons for leaving out information in discussion with their doctors: not confusing the doctor, complementary and alternative medicine, and symptoms or history linked to the mind. All such forms of control strategies involved avoidance of potential conflict within the clinic. This was done through leaving certain elements outside the realm of biomedicine, thereby attempting to circumscribe the influence of disciplinary power.

<u>i. Confusing the Doctor</u>

Women spoke of not sharing symptoms they felt were unrelated to endometriosis. This reflected the fear that doctors would not focus on the symptoms that were truly

bothering them. They thought that '*doctors might get confused*'-SSI by the extra information. While this was not a subject often spoken of during interviews, it was a common discussion during support group meetings. A discussion in the support group about what to tell your doctors one day concluded that '*you should not tell your doctors everything; it just confuses the issues'*-F. The implication was that doctors often got off track and started to look for other diagnoses or began to label women as having a psychological problem. Women were afraid that doctors would abandon the endometriosis label and look for another cause for the symptoms they were reporting, placing them back in the a-diagnostic category.

ii. Complementary and Alternative Medicine

Most of the women I spoke to reported using some form of complementary medicine as a way of '*getting by*'. They saw complementary medicine as a means to feel better. They often changed their diets to look for '*intolerances*' or foods that exacerbated their endometriosis symptoms. This diet was not the same for all the women, but varied from gluten free, to vegetarian, to vegan, to lactose-free. Women also began using other forms of complementary medicine such as a TENS (transcutaneous electrical nerve stimulation) machine, acupuncture, or acupressure.

Despite the widespread use of these complementary medicines, women were reluctant to share this information with their medical providers. They pointed out that doctors would be judgmental about their use of complementary techniques. They were afraid that the doctors would treat them differently and no longer take them seriously. They also thought that complementary medicine was outside the remit of their doctors. Alice explained:

> *I think I've had a lot of personal experience now with complementary therapies have helped me uh with my pain such as massage and acupuncture. They really, really do help me personally a lot and I know doctors can't prescribe such things but I've only had one doctor talk to me about using complementary therapies alongside our hormonal drugs or anything like that and he's openly said I want you to go and get some complementary therapy, get as much as you can, as much as you can afford and I know doctors don't often talk about complementary therapy because it's not proven I suppose in a scientific way to*

> *be helpful um but I think many women will find benefit in complementary therapies.*-SSI

Alice suggested that doctors could not prescribe complementary therapies such as massage or acupuncture but she did believe that they should at least discuss the possibility of using complementary therapies in addition to medical treatments for endometriosis.

Women with endometriosis often explained that doctors were pushing more biomedical treatments over complementary treatments even if the woman clearly did not want the traditional treatments. This did not just apply to strictly complementary treatments but also to referrals to a pain clinic, for example. Judy explained that in looking to use a TENS machine, she wanted a referral to the pain clinic. She explained:

> *…but the GP said you do not need that – I can just give you morphine – that is not what I was looking for – I was looking for acupuncture or a TENS machine not pills – I got my back up – had to fight/defend myself to get this referral eventually got it but the GP put a very negative twist on the idea of pain clinic – ie said all they would do is give me counselling.*-F

iii. Symptoms or History Linked to the Mind

Women also were afraid to speak of any symptoms or history that might sway doctors to see their condition as linked to their minds, which might move them back into the a-diagnostic category. Sharing any history of physical abuse or rape was treated with great hesitancy. Women felt uncomfortable discussing such experiences with their clinicians for fear that their pelvic pain would be labeled as 'psychological' and not linked to endometriosis. They were very concerned that such a history would invalidate any previous diagnosis of endometriosis. For example, during a support group meeting, Alice spoke of her rape experience. She was unwilling to discuss it in our personal meetings, and therefore it seemed a sensitive subject for her. When she brought it up in the support group meeting, she explained that it was her first time speaking of it without bursting into tears. She explained that she was raped in 'uni', and emphasized that she was sure it was not affecting her pain.

Women were also concerned that doctors might construe any acknowledgement of mental health matters as an admission by the women that all their physical symptoms of endometriosis were actually due to a psychiatric problem rather than the endometriosis itself. Women went out of their way to make clear that any use of anti-depressants was because of pain and not due to depression. There was a distinct fear that such information would end up in their medical records. They were concerned that future visits and doctors would be tainted by this information. This knowledge was thought to represent an obstacle to care and treatment of endometriosis. Even women who did openly admit that they were at times depressed were hesitant to report these symptoms to their clinicians for fear that the information would be used against them. Thus, women with endometriosis were not only actively avoiding instances of conflict, but surveillance and exertion of biopower through their doctors.

2. Unplanned Control Strategies

The following three types of control strategies utilized during the clinic visit were not pre-planned and were largely actions that the women appeared to be unaware of. When women felt uncomfortable in the clinic visit, they began utilizing these strategies. The presence of these elements within the clinic visit represented a communication breakdown between doctors and patients.

a. Limiting Eye Contact and Answers to Questions

In some clinic visits, women reported feeling upset or not heard. This appeared to be an emotionally negative reaction to the clinic visit. For example, Pamela had had symptoms of chronic pelvic pain for years. She was seen by a clinic registrar who directed the interaction, posing closed-ended questions and not allowing her to have her say. She asked about the side-effects of zoladex[8] three times, but was told to ask her GP. During this visit, a plan was made for her to have a hysterectomy. At this point in the interview, Pamela began to roll her eyes at me, started to cry, and limited eye contact with the doctor. She went on to tell me that the doctor appeared uninterested

[8] Zoladex is a Gonadotropin Releasing Hormone-agonist, a hormonal drug often used for treatment of endometriosis.

and pushed for the visit to move forward. Pamela left the surgery feeling upset. She felt disrespected and dismissed. She was seeking more attention and personal recognition. Yet, the registrar dictated a summary of the clinic visit stating: '*patient happy with the plan*'-F.

Pamela then returned for a pre-assessment visit to prepare for her hysterectomy. At that time, she spoke to me about her experience and her fears regarding her upcoming surgery. She explained that she did not know what would happen to her. She pointed out that when she left the last clinic visit, she went to see her mother in an attempt to feel better about the experience. She left there feeling worse, as her mother asked her questions such as '*what about HRT, remember we have a family history of breast cancer*'-I. During the pre-assessment visit, she looked to have her questions answered. Unfortunately, again she concluded that the nurse '*just shut me down*'. '*Why couldn't she answer my questions about the surgery itself?*'-I she asked me. She was given leaflets about hysterectomy, but the nurse suggested that these should have been provided in the clinic. Interestingly, in this case the doctor did not appreciate the impact of her behaviour on Pamela. She (the doctor) remained unaware of what had transpired between her and the patient. Other doctors who did recognize the effects of their behaviour on the patient generally took steps to redress the communication break-down. This resulted in the women's feeling happier after visits.

Pamela was upset in her interactions with the doctor and the nurse. She wanted to change the medical professionals' behaviour towards her. But she felt powerless. The result was the use of control strategies such as limiting eye contact, rolling her eyes and crying. She hoped that the professionals would have noted her effort to draw attention to her negative feelings during the interaction. This did not occur.

b. Walk-Out

While I did not witness a woman walking out of her clinic visit during my fieldwork, women did consider walking out as an option if they were particularly upset by the visit. However, they were concerned that this strategy would have negative consequences for

them. In support group discussions women with endometriosis were afraid that by walking out, they were ultimately limiting their access to any care at all. The consensus was that '*there are only so many doctors who can treat endometriosis*'. In addition, women were afraid to be labelled a 'difficult patient'.

C. Control Strategies After the Clinic Visit

Patients used a long list of control strategies after they had left the clinic, including through Endometriosis UK, which will be reviewed in detail in Chapter 9. The majority of these actions were employed without medical professionals' being explicitly aware of them. Instead, these strategies, forms of resistance to biopower, appeared to be used as ways of avoiding negative experiences with doctors, often with the effect of exiting the medical system either permanently or temporarily.

1. Make a New Visit

Women with endometriosis considered making an additional appointment if they were unhappy with the way the previous visit had gone. This was usually a reaction to their feeling that they needed more time. They considered this as an option, if they felt listened to, but simply did not have enough time to ask questions. In addition, some women wanted to research the treatment options set out by the gynaecologist. Those who did make new visits did not see the original visit as negative, but rather as too short. However, some women also spoke of wishing that they could make another appointment but feeling as if this was not an option. They worried about limited NHS resources and cited concerns over short visit times and waiting lists. Women often discussed having a social responsibility to limit their use of NHS resources.

2. Exiting/Switching Doctors

If a woman complained that she was uncomfortable with the advice given by her doctor, she often considered not following it. This was a subject discussed in support group meetings. They spoke of the necessity to switch doctors if they *'did not trust*'-F their doctor, felt dismissed, or were not listened to. They often discussed these things

amongst themselves in support group meetings or online when it was appropriate to switch doctors, and which doctors it would be good to switch to when such a decision was taken.

While they often agreed that switching doctors was a good idea, the discussion usually moved to the practicalities of getting transferred to another gynaecologist through the NHS. This was a complicated procedure that depended on their interaction with their GP. Because of previous negative experiences with doctors, this discussion with the GP was approached with particular apprehension.

3. Avoiding Doctors and the Medical Community

Negative experiences with doctors sometimes influenced the women to avoid seeking medical care. It was common to hear the women with endometriosis speaking of '*dreading*' interactions with medical professionals. Valerie, for example, explained that:

> *To be honest, I have often dreaded going to GPs and consultants because as an endo sufferer I had to go so often. I worried that I would be seen as a hyp[o]c[h]ondriac, with my repeated GP visits*. -Q

Audrey described avoiding visits to A&E (Accident and Emergency). She expressed the following:

> *Because I'd been made to feel that it's period pain. What do you expect anyone to do? You've just got to wait and see and I've always been a bit you only go there if you really have emergency in hindsight I should have gone because I was in so much pain I was I couldn't move I was doubled over I was vomiting you know I was taking all the pain-killers I could and nothing was helping um but I thought if I went the doctor's just gonna get annoyed with me for going you know when he said he'd refer me so you know I didn't really know what to do and I was still losing massive clots that I was having to get rid of myself in order to actually have my period and I was scared of infection and all sorts of stuff.* -SSI

Several women spoke of wanting to avoid the medical community altogether. While few of them ultimately took this option, they did, however, explain that they were dependent on the medical community to maintain their health. So they were unable to

divorce themselves completely from a medical system that provided them at the least with the possibility of feeling better.

Only one woman in my study said that she had decided to avoid the medical community as a whole with regards to her endometriosis. She explained that she was willing and able to do so because she had switched solely to alternative medicine as a way of controlling her endometriosis.

4. Complaints

Women often complained about their experiences with doctors. This was accomplished through several means, including discussions with each other in support groups. The complaints resulted in their implementing the control strategies we have already discussed.

Women also acknowledged the possibility of making an official complaint to the NHS, but resorted to this only in dire situations. They were afraid of the consequences of their actions, making a bad situation worse, and alienating their only access to care. The complaint was often considered after women had moved and as a result changed GPs or gynaecologists. One spoke of her complaint made to the NHS but was concerned about my disclosure of such information for fear that it would negatively impact her in some way.

D. Fear of Being Labeled a Difficult Patient

Despite the use of the above control strategies, patients felt there was a balance to be maintained between being 'an empowered patient' and a 'difficult patient'. While they were concerned about being truly listened to and taken seriously, they were also afraid of being labeled a difficult patient. They worried that the latter situation might mean medical professionals would listen to them even less. This fear parallels findings by Asbring and Narvanen (2004) who explained that:

> It was especially when the doctors' medical competence was questioned that the patients' … strategies evoked negative sanctions from the health care

> providers, which, according to the interviews, included expressions of irritation, reproof, direct reprimand, or making it clear to the woman in some other way that she was a difficult patient. Negative sanctions can be seen as a punishment system that aims to normalize a person's behavior according to the health care provider's values about what is appropriate. Such sanctions might arise as a consequence of the women's using power/counterpower in the interaction, but also, for example, when they have proffered their own suggestions regarding the cause of the illness or interventions. (Asbring and Narvanen 2004: 235)

It is worth noting, of course, that these authors underlined the connection between the 'difficult patient' label and its provoking retaliation from care-givers who in turn could impede the patient's access to good care.

III. Healthcare Professionals' Control Strategies

Healthcare professionals also exhibited feelings of powerlessness because of disciplinary power and associated use of control strategies. While these feelings were generated by reasons different from those that evoked powerlessness in women with endometriosis, the helplessness of doctors and nurses still affected the professional-patient interactions during clinic visits.

A. Nurses

Nurses' use of control strategies, unlike patients or their gynaecologist colleagues, was a tool by which disciplinary power was employed to force these other two groups to behave appropriately. The nurses in the clinic studied in this research generally had limited contact with women with endometriosis and experienced some of the most difficult interactions with endometriosis patients. This was largely because the doctor might ask the nurse to join the visit if a 'difficult interaction or patient' was expected. Nurses were outside the clinic room both before and after a visit and could therefore be witnessing the results of a negative interaction.

1. Roles in Clinic

One of the main jobs undertaken by nurses was to maintain the list of patients visiting the clinic on a given morning or afternoon. This task consisted of monitoring which

patients were in the waiting room, who was seeing a doctor (this was noted by two intersecting ticks next to the patient's name), the patients who had already left (this was noted by crossing off the patient's name), and who had not attended (DNA[9]). Nurses were also there to help with any physical exams needed. The four roles that nurses undertook that I describe here in more detail served to pressure gynaecologists and patients into conforming to expected clinic behaviours.

a. Time-Keeping

The head nurse in the clinic kept everything running on time. If the clinic became more than fifteen minutes behind schedule, she began telling all the doctors to start seeing patients faster. Some registrars were pressured by their schedule, noting that such comments were often directed at them. It bothered them when they thought that certain patients needed more time. This tension created friction between some doctors and the nurses, as the nurses exerted their influence here.

b. Pre-Screening

Nurses fulfilled an additional but unofficial role within the clinic. This involved pre-screening patients who were on the list to be seen by the doctors. Nurses generally provided a brief description of the patient and her complaints. While the information was usually linked to the patient's previous medical history, the nurse would often add more information. This included how many people were with her, how long she had been waiting, and previous experiences the nurse had had with the patient. This explanation included comments about her previous visits, judgments about her personality as well as the validity of her complaints. While some of these comments could be about how lovely the patient was, thereby setting a standard for what might be considered a 'good' patient, some comments reprimanded or otherwise corrected someone who was not acting in the 'appropriate' way, yet another form of disciplinary power.

[9] DNA (Did Not Attend)

c. Non-Attendance

Nurses became very angry while discussing any patients who were classified as DNA (Did Not Attend). The term DNA was used as both a verb: 'to DNA', and as a noun: 'a serial DNAer'. DNAers were criticized for wasting NHS resources. The nurses estimated waste due to DNAers to cost the NHS billions of pounds annually, and directly linked non-attendance to NHS debt. Patients who DNA'd also seemed to be attributed certain intrinsic qualities, including laziness, disrespect for others, and lower socioeconomic and educational status. One nurse did not understand why someone who had previously DNAed would then come back for a visit. Questions were asked such as: *'Is it really so difficult to pick up the telephone?'*-F She did not want to treat DNAers in the same way as other patients: '*Why should we respect them if they do not respect us'?*-F Such notions of the DNAer as someone with bad character express disciplinary power through expectations of appropriate conduct. The nurses connected patients with unexplained chronic pelvic pain (a part of the a-diagnostic category) with increased DNA activity. Thus, disciplinary power reasserted the legitimacy of the existence of the a-diagnostic category and women's remaining there.

d. Overhearing Negative Patient Comments

As the nurses spent more time in the hallway than doctors, they were more likely to overhear comments by patients and their families (or accompanying individuals) who were speaking to each other while in the hallway on the way out. Nurses were therefore often the first to report a negative patient experience to doctors who had, until that point, felt that the interaction with the patient had gone well. This often elicited surprise and sometimes anger from doctors towards the patients. However, at times the response by the doctors to this news was: '*to be honest, I am not surprised. I did not think that went very well*'-F. However, such responses led to feelings of helplessness as these doctors expressed a desire to improve the interaction with that particular patient without knowing how to go about it. Here the disciplinary power by the nurses was not focussed on the patients but on the gynaecologists, leading to self-surveillance in which doctors believed they did not fulfill their role as doctor.

2. Control Strategies with Patients

Nurses displayed several control strategies towards patients. These included moving a patient down the list and speaking badly of her to doctors. A nurse might move a patient down the list if she decided the patient had not behaved appropriately. Moving a patient down the list largely meant that the patient scheduled to be seen, say at 11:15, would be seen after all the other patients also listed at the 11:15 time. Alternatively, depending on how much she felt the patient should be punished, the nurse might move her to be seen at 11:30 or even 11:45. Reasons for moving a patient 'down the list' were varied, but they included previous negative behaviours such as DNAing, arguing with the staff outside, being late, or questioning the lateness of the clinic. In other words, if the patient had in some way offended the nurse, she would be punished. Nurses would also speak badly of patients to gynaecologists. Because nurses would usually read a patient file before a gynaecologist came to it, nurses had the opportunity to warn doctors of the patient they were about to see. All these forms of control strategies deployed disciplinary power on patients judged to have behaved inappropriately by being late, DNAing previously, or arguing with staff.

3. Control Strategies with Registrars

Nurses also employed control strategies with doctors and especially with registrars. Just as patients could be 'punished', registrars who were not liked by the nurses also were more likely to be punished than their counterparts who were on good terms with the nurses. I observed a variety of commonly used control strategies that punished registrars.

For example, nurses often reported a registrar's lateness to his or her superiors. This usually happened if the registrar did not already have a positive reputation. If the registrar were considered reliable, the nurse would wait longer to report the absence. Negative reputations generally stemmed from bad relationships with the nurses. Such reputations developed from the registrars' ordering instead of politely asking the nurse to do something, and their being ignorant of the protocols of how to order laboratory tests, scans (ultrasounds), MRIs; or laparoscopy procedures. However, reactions to

their ignorance of protocols depended again on the registrar's personal relationship with the nurses as well as the length of time the registrar had been participating in the clinic. The newer the registrar, the more patience was accorded to the lack of knowledge regarding protocols. Thus the discipline (official reporting to a superior) appeared to be about lateness, but was actually linked to what was considered inappropriate registrar behaviour.

Nurses might also use informal evaluations of registrars as a control strategy. Consultants would often come in at the beginning of the clinic and ask '*who have we got today?*'-F. The question would be to assess how many registrars and medical students were staffing the clinic. In response to this question, nurses included evaluations of the registrars they were familiar with. These evaluations usually included the level of each registrar's knowledge of the protocol system, the relationship or ability to get along with the nurses, and the ability to move the clinic along quickly. The task of getting 'patients in and out the door' was largely dependent on two separate elements: first, the length of the clinic visit itself; and second, the ability to get through the clinic visit without needing help from a superior such as the consultant. Therefore, those registrars who rarely asked for clinical help were considered superior, reinforcing an expectation of medical knowledge. This expectation of high levels of clinical knowledge without need for supervision may have fostered a system in which registrars were uncomfortable asking for help even though they were in situations that left them feeling uneasy and beyond their clinical experience, a form of self-surveillance.

In the clinic, nurses had set up a system that served hot drinks, tea and coffee. Each member of the nursing staff contributed a certain amount of money each month to defray the expenses of the refreshments. Those registrars who were friends with the nurses received free coffee or tea. Those who were considered neutral parties were asked nicely to pay for the drinks they consumed. Those who were disliked could be yelled at or strongly reprimanded for attempting to take a hot drink without paying for it. Consultants were always offered free coffee or tea. However, there appeared to be an understanding that on the 'nurses' day' the consultant would contribute a significant

amount to the 'kitty'. Thus, access to the hot drinks served as a form of discipline and surveillance linked to what was considered appropriate behaviour by registrars and consultants.

This surveillance and discipline established a hierarchy of registrars which was also applied in other domains. For example, nurses generally assigned clinic rooms based on the notion of 'first-come, first-served'. However, those registrars who were better liked were given the 'better' rooms or the rooms for which they had previously shown a preference.

Regarding the treatment of endometriosis patients, well-liked registrars were more likely to be allowed by the nurses to choose the patients they would prefer to see. Patients were generally considered more desirable if they were likely to be simpler cases. More complex cases and cases that were thought to take longer would be less desirable. Women with large files, or who had previously come in with the same complaint were considered complex cases. Patients with undiagnosed conditions or conditions that were difficult to treat were considered less desirable. While we will explore this specifically with regards to endometriosis patients in the section on doctors' feelings of powerlessness, this generally meant that it was rare for a registrar to choose voluntarily to see an endometriosis patient or a patient with chronic pelvic pain. If the registrar needed help, it was more likely to be given readily if the personal relationship between nurse and registrar was good. The result here was a dual exertion of disciplinary power. Patients were censured for being 'difficult or complex' cases. Doctors were effectively punished by being given the less desirable patients. Additionally, doctors were discouraged from seeking a supervisor's help with a difficult case.

4. Control strategies with Consultants

Nurses did not employ control strategies with consultants in the same way that they did with patients or registrars. Instead of overt strategies, nurses did talk amongst themselves about the consultants and only complained about them with each other.

Their tone was more, '*yes we may not like this or that but that is the way it is*'-F. It was not seen as acceptable to question openly consultants' behaviour or decisions. To change a consultant's behaviour required going above that consultant's head to administrators. Such complaints were relatively serious and rare. This may have resulted from self-surveillance and from disciplinary power exerted on nurses such that they felt it was unacceptable to behave in a way that overtly showed any questioning of consultants.

B. Gynaecologists and Feelings of Powerlessness

1. Registrars' Control Strategies

John, the registrar, stands by the patient files in the consulting room where the nurse has set up her nurses' station. He is actively trying to avoid any large ones, ones that appear to be one full ream of paper or that might have more than one volume. He realises that the 5 cm file in front of him is his next patient. He grimaces, sighs and looks visibly annoyed. He asks the nurse 'is Mr. Xavier free? Maybe he can see her instead?'

John's reaction was similar to those of other registrar working in the clinic. Each patient had a file in which the patient notes were kept. For most women with endometriosis this file was very large, several cm thick. Some women even had several volumes in their file. As registrars often had not seen the patient previously, the prospect of having to read and digest such a complicated case in just five or ten minutes was very daunting. Seeing such a large file would elicit those deep sighs, and negative facial expressions described in John's story.

a. With Consultants

John's direct avoidance of the case by attempting to pass on the patient to the consultant happened over and over with other registrars as well. Registrars would often attempt to pass on endometriosis patients to the consultants, citing both the consultants' knowledge and interest in the disorder. While this method of avoiding the patient sometimes worked, the success of the technique was often determined by the nurses.

Other than this, registrars rarely employed control strategies, generally deferring to the consultant whom they saw as having greater technical knowledge and clinical experience with endometriosis patients.

b. With Nurses

When giving the patient over to the consultant gynaecologist did not work, John then took the next step. Sighing, he said 'Well, glad I had my coffee. This is gonna take a while.' This was the next control strategy to use while facing potential failure to 'cure' or 'treat' the patient. Like John, some registrars acknowledged that endometriosis patients often required longer clinic visits. These registrars were conflicted as to whether to spend the extra time with the patient and accept the negative consequence that this entailed (that is, upsetting the nurses), or making the visit short and risking the patient's becoming upset. Registrars concluded that either way, the outcome would be on some level negative. However, some felt that it was important to spend the time with patients, as this was the only thing they could in fact offer, time and a sympathetic ear.

Patients with complex cases and correspondingly large files were considered less desirable by both registrars and nurses. The professionals avoided this type of patient if possible. Practically, this represented an avoidance of patients with endometriosis and of patients who were presenting with undiagnosed chronic pelvic pain. I believe this avoidance of endometriosis patients stemmed from the feelings of powerlessness this interaction would engender. This was due both to the medical complexity and the emotional difficulty associated with such patients and an associated expectation that as doctors they should be able to diagnose and treat/cure patients, an expectation linked to the disciplinary power of biomedicine.

Registrars received little teaching about endometriosis from consultants, and the teaching remained at a superficial level, which may have contributed to the registrars' sense of powerlessness. Consultants stated that endometriosis was difficult to explain because of its intrinsic controversies. There was never an easy explanation that could

be given to explain endometriosis. It was quite striking that I saw little teaching by consultants to other medical professionals regarding endometriosis. This might have been due to lack of time, and the general feeling of being rushed in the clinic. Teaching tended to focus on treatment rather than on the pathophysiology of the disease. The treatment plan for pain due to endometriosis usually involved hormonal treatment as a first step and then surgical treatment as a second step. Such limited teaching may of course have contributed to feelings of insufficient knowledge about endometriosis, which added to notions about the complexity of the endometriosis patient and body, and to ideas related to the inability to fulfil their role as a doctor who diagnoses and cures effectively.

Women with endometriosis were expected to cry and be upset more often than others presenting to the clinic for other reasons. Registrars were uncomfortable dealing with the grief associated with endometriosis patients and many stated that they had to be in the mood to deal with this diagnostic group. One registrar explained that she had chosen obstetrics and gynaecology because it was a relatively happy specialty, one in which you could easily fix women's problems. But for her, a visit with a woman with endometriosis was likely to be filled with sadness and tears. She stated that *'It takes a lot out of you'*-I to see these patients.

Registrars were often also uncomfortable with the notion that they were unable to '*fix*' patients with endometriosis. Jessica, another registrar, remarked: '*They come to us, but what can we do*'?-I This feeling of powerlessness was common and always expressed with much sadness. Registrars would, therefore, often barter with each other to decide who would take such a patient, a process often directed by the head nurse. It was in an attempt to avoid dealing with what they considered to be a difficult and emotionally draining subset of patients, but also a way around the disciplinary power often exerted through nurses.

2. Consultants' Control strategies

The powerlessness felt by gynaecologists depended on their level of training. The more senior, the less gynaecologists felt powerless with regards to issues of knowledge. But it may also have reflected socialization into the medical system. Consultants showed less powerlessness during their clinic visits with regards to their interaction with endometriosis patients. However, they did discuss certain issues during their interviews with me, including cases in which they felt they could offer nothing to patients. This took place in a casual way, with qualified statements such as '*that's life*'-F. Here, consultants openly acknowledged the limits to their ability to help this subset of patients. This was explained as a lack of medical knowledge about the disease with subsequent limited treatment options. Overall, they did not link their inability to help with personal failure, as did the registrars. Instead, they utilized control strategies to subvert the disciplinary power imposed on them. To escape expectations of treating or curing a patient, they removed patients from their 'list'.

Consultants spoke of not keeping patients on the 'list'. The 'list' referred to names of women who were patients and were given repeat visits without needing a new referral from their GP. Having a space on the list was a valued privilege. Spaces were limited. Dismissal from the patient list was often used for two separate reasons. The first was a direct response to patients' expression of potential non-compliance, whereas the second was linked to the feeling there was nothing more to offer the patient.

a. Patients' Potential Noncompliance

Dismissal of a patient from the list by a consultant often occurred in response to women's direct opposition to either being forced to make an immediate decision, or to their deciding to do nothing at the moment. Consultants often responded to patients' uncertainty about following medical advice by dismissing them from the list and telling the patient to '*come back when you think you want to do something*'-I. This resulted in patients' feeling that they had been reprimanded for being unsure of what to do and for wanting to take some time to consider the options. The patient was dismissed from gynaecological care directly because of her resistance to the disciplinary power exerted

on her to make a decision quickly. A plan was set out about her care and about her body. The fact that she did not agree right away caused her to feel excluded from the biomedical system.

The clinic was set up so that women had little time to make an informed decision about their care. Some women attended the clinic, and within five minutes of being told their options for care, which for example included do nothing, take hormones, have an injection, or have laparoscopy/keyhole surgery, would have already consented to surgery, and been shepherded off to their pre-operation assessment. In this situation, if women were attending the clinic alone they were unable to discuss the treatment options with their loved ones or others they might take counsel from.

This raises issues directly related to the ethics of potential forced decision-making. By requiring women to make quick and instantaneous decisions on their care, women often felt required to make a decision without properly considering their options. They spoke of wishing they had time to ask more questions about the impending procedure or medical treatment they had somehow accepted. This often resulted in re-examining their decision at a future time, and sometimes deciding against the medical advice. Thus, they resorted to an avoidance and use of other control strategies at a later time that would perhaps not have been necessary if they had been able to spend more time with the doctor to ask more questions, or if a follow-up appointment had been offered with an opportunity to explore their options more fully.

b. 'There's Nothing We Can Do'

The second main reason for dismissing a patient off the list represents a response to feeling unable to help the patient with anything. Consultants believed that patients who could not be helped were essentially taking up space that could be better filled with someone who might benefit from their care. One consultant explained that:

> *We can often keep patients on the list that we don't do much for we could have an entire clinic of patients we just talk to if we let it. That's why some endometriosis clinics have nurses who talk to all the patients and the surgeon just comes when the knives are needed.*-I

For him, his job as a consultant should ideally be to perform surgery. He felt that leaving a patient on the list unnecessarily kept other patients from accessing care. However, this care appeared to be linked solely to surgical intervention, as opposed to any form of verbal therapy that he felt was not or at least should not be his job.

Patients in this situation often spoke of feeling dismissed and left to their own devices. Elaine, for example, explained that the doctor was saying '*Discharge! You're out of my hands now hurray!!*'-SSI. For her, the doctor was happy to be rid of her. Pain consultants who felt that patients were sent to them under similar circumstances also discussed this situation. They explained that patients were likely to feel 'dismissed' and 'dropped' and worried that this would affect their ability to trust all medical professionals.

Removing patients from the 'list' therefore effectively banished patients from the biomedical system (with relation to gynaecology at least) placing patients into a 'zone of invisibility' or 'zone of exception' as Jacob and Foth (2013) described where healthcare professionals label someone as the 'a-potential patient', the patient with no possibility for recovery. This moves women with endometriosis back into the a-diagnostic category, allowing consultant gynaecologists to re-undertake their role as a doctor who successfully treats, cures, and diagnoses. Those patients who force the consultant gynaecologists out of their ideal roles, roles biomedicine expects of them, and that which biomedical disciplinary power directs, are themselves then forced out of the system in order for doctors to maintain their expected roles.

C. Control Strategies Used by Healthcare Professionals in General

1. Dismissing Patient/'Lay Knowledge'

Both consultants and registrars sometimes dismissed patient knowledge. They did both within the clinic visit and while speaking afterwards to others. Consultants believed

that their knowledge of endometriosis was more valuable than 'lay' knowledge, despite patients' presenting to the clinic with detailed information and sometimes copies of medical journal articles. Situations in which doctors refused to accept lay knowledge are well documented (Whelan 2007), and of course linked to notions of disciplinary power in the clinic where patients are expected to take on biomedical understandings of disease (Lupton 1997).

Women with endometriosis often spoke of experiences related to doctors' dismissing their knowledge and experience of endometriosis. Judy explained that:

> *They don't um you feel like you've just been put through one after the other don't care about how it's affecting or explaining what your options are. His manner was I don't care all the time it was about him showing that he's the clever one, he knows what he's doing, doesn't matter what you think, you know he doesn't really want to know he's gonna tell you how it is and you gonna put up with it regardless and he doesn't take any time to consider your feelings um the amount of times. He's really upset me you know and I'm not somebody who gets easily upset really but in a certain situation where you're struggling with something like endometriosis and the effect it's having on your life you need someone to be able to cause he's the expert you need to be able to talk to him and him being short with you or not listening thinking he's superior and doesn't need to talk to the minions that are his patients is you know very difficult.*-SSI

Her consultant wanted to show that he was the '*clever one*' and was not interested in taking the time to understand her feelings and the effect endometriosis was having on her life. He was asserting his superiority as the expert over her, a patient, thereby exerting disciplinary power over her.

2. Post-Visit Complaints

Medical students, consultants, registrars and nurses would all complain to others inside and outside of their groups if the visit had not gone well. Consultants stated that uses of control strategies made the visit uncomfortable. Most often, reasons for such complaints resulted from the perceived use of control strategies by patients.

D. Healthcare Professionals' Responses to Patients' Control Strategies

Healthcare professionals experienced increased powerlessness or at least increased negative feelings towards patients' strategies of asserting themselves and representing their interests. For example, healthcare professionals resented patient requests for continuity in their care by seeing the same doctor. Both nurses and doctors considered this to be a nuisance that slowed down the clinic. This in turn created more frustration especially on the part of the nurses and the doctors (registrars) whose schedule was managed by the nurses. Medical professionals were also uncomfortable when patients came in with folders of information. The nurses would announce the arrival of a patient with a folder and this advanced warning was not always appreciated by the doctor who received it. Some doctors felt it functioned as a negative pre-judgment of the patient and of little or no clinical use.

Some professionals believed that, at best, a patient who came with high levels of preparedness needed more time, and at worst, was getting ready for a battle not unlike Kleinman's (1988) description of, within a chronic pain clinic, an escalating battle between doctor and patient. This type of patient was thought to be upsetting the balance in the relationship, not allowing the doctor to control certain elements of the clinic visit. This situation created friction, as the doctor still had to perform tasks such as history taking and/or a physical exam.

> *Consultant: I tried to listen but she wouldn't let us direct the interview*
>
> *Medical student: I've never seen a consultation with a patient who brings a folder go well… she wanted to control the consultation, she had all these bits of paper and kept referring to them but was not organized and couldn't find what she was looking for*
>
> *Nurse: when she left she looked upset her husband was saying to her 'don't listen to them they don't know what they're talking about'*
>
> *Consultant: What? who?*
>
> *Nurse: You*

> *Consultant: Me? I didn't know what I was talking about? She has been suffering from symptoms of vaginal discharge for 35 years on and off but it is nothing serious.*-F

In this example, the patient is employing her own control strategies to escape from the a-diagnostic category. At the same time, the doctor responds to this negatively because the patient is not fulfilling her role as patient and is experienced as oppositional; and the doctor is not able to carry out his expected tasks such as taking a detailed medical history. The gynaecologist thus feels pressured to diagnose and treat due to the disciplinary power exerted here. Disciplinary power is exerted by the gynaecologist and on him.

There were, however, other control strategies that patients employed while healthcare professionals remained unaware of them. For example, healthcare professionals seemed oblivious to patients' uses of complementary and alternative medicine. Patients felt that changes in diet or exercise routines either did not fall under a doctors' purview, or they were afraid of negative remarks from healthcare professionals. The rationale appeared to be: '*well they are likely to react badly and besides it has no direct effect on the biomedical treatments we are currently trying does it?*'–F Patients would sometimes switch to another doctor or decide to leave the biomedical system all together without their doctor's knowledge. These control strategies represent forms of resistance to disciplinary power that happened outside the medical system and therefore outside of the healthcare professional's view.

E. Chronic Pain Clinic Healthcare Professionals

It did not appear that the healthcare professionals from the chronic pain clinic felt the same level of powerlessness as did their gynaecologist counterparts (something that certainly warrants further exploration in future research). This may have been because professionals from the chronic pain clinic did not feel the same need to be able to 'fix' or 'cure' their patients as did the gynaecologists. Instead the chronic pain clinic professionals spoke of attempting to make patients more comfortable and more able to function through giving patients their own tools. The chronic pain clinic interventions

seemed to reinforce patients' power over their own bodies. Perhaps by sharing the power with the patient, the healthcare professional avoided the power struggle and felt more useful to the patient.

Health professionals in the chronic pain clinic offer an instructive comparison to those in the gynaecology clinic. The differences highlight the importance of clinical context and the contrasting values of different sub-fields in medicine (Scheper-Hughes 1990). Focus on cure versus for example care, or on diagnosis versus focus on symptomatology change the notions of what roles doctors are expected to have and to uphold. Thus, the disciplinary power the gynaecologists are subjected to may be quite different from that experienced by their counterparts in the chronic pain clinic.

IV. Conclusion

In this chapter, I have discussed disciplinary power by examining the use of control strategies within the clinic. Both doctors and nurses were instruments through whom disciplinary power was exerted on patients. But the picture was more complicated than this. Disciplinary power was applied through nurses onto gynaecologists as well. Thus, both doctors and patients experienced feelings of powerlessness because of disciplinary power within the clinic. Both groups employed control strategies in response to these feelings. Patients' strategies included taking down the 'mask of health' discussed in Chapter 7, educating themselves about endometriosis, creating a log of all pain experiences, attempting to see the same doctor at each visit, switching doctors, deciding to use complementary medicine, making official complaints against the NHS, and deciding to avoid doctors all together. Gynaecologists' use of control strategies involved dismissing patients from the list, disregarding patients' lay knowledge, and airing post-visit complaints.

Unfortunately, the deployment of control strategies by both groups resulted in the other group's feeling more powerless. Therefore, we saw a cycle in which the feelings of powerlessness, linked to the constraints of disciplinary power, fueled the use of control

strategies, and their use aggravated the feelings of powerlessness that caused them to be used in the first place.

The result of this escalating use of control strategies was that women with endometriosis transitioned back into the a-diagnostic category through their exclusion from part of the medical system. This effective banishment from the gynaecology clinic may have come from the patient – with her control strategies often linked to avoidance of the medical system. On the other hand, it may also come through the patient's being forced outside the clinic by the doctor. When the gynaecologist took women with endometriosis off his list, the doctors were the link through which disciplinary power was exerted on the patients. The doctors were reacting to the systemic disciplinary power within biomedicine that required them to cure the patients in front of them. Exclusion from the clinic meant the endometriosis label and associated treatment were further out of the patients' reach. Thus, women redoubled their efforts to obtain the label.

CHAPTER 7

Stigma, Gender, and Endometriosis

I. Introduction

Annemarie Mol (2002: 33) reminds us that enactments are 'techniques that make things visible, audible, tangible, knoweable'. In this chapter, I concentrate on two important elements (stigma and gender) that influence enactments both inside and outside the biomedical clinic. The following quotation from Mia is illustrative.:

> *I struggled socially in my teens because I didn't go out as much as my friends. It also made things tricky with gatherings if I'd had to cry off certain activities and been unable to explain why because I don't necessarily know people that well, or because middle-aged men are involved who would be uncomfortable with being told about "women's things"!*-Mia (Q)

'Women's things' are not to be spoken of, to be talked about, or to be mentioned in the wrong company. Thus, Mia struggled to explain her absences and her inability to participate in certain activities. This example is only one of many where stigma linked to endometriosis reared its head. Stigma relates to society's recognition of 'some distinguishing attribute of an individual, which consequently devalues an individual for possessing this norm-violating characteristic' (Conley et al 2013:2). A stigmatized individual 'is devalued, spoiled or flawed in the eyes of others' because of her 'membership in some social category' (Crocker et al 1998: 504). Stigma also relates to the external mask we show the world. It is this presentation of ourselves, this mask, this persona that others judge us by (Biggs 1997). This mask becomes a tool that can be used to conceal the norm-violating characteristic (Jung 1967).

I am concerned with the concealment of endometriosis and its associated symptoms. This relates to what Goffman (1963:4) called the 'discredited' and the 'discreditable'. The 'discredited' is an element that stigmatizes an individual who is already known either by the element that is visually perceptible (for example by the use of a wheelchair) or that is cognitively perceived (for example the element has been disclosed to someone). The 'discreditable' is the element that could stigmatize an individual if it were known. Therefore the risk of being discredited represents the 'felt stigma'. It is the unknown risk of others' knowing about the endometriosis and the associated self-dsiciplining by women that is at the forefront of this chapter.

Coming back to Mia's narrative, what 'women's things' is she speaking of? My participants spoke of stigma linked to three main symptoms of endometriosis: severe pain during menstruation, pain during sexual activity, and infertility. In this chapter, I examine how stigma, associated with three aspects of endometriosis (menstruation, sex and childlessness), limits women's access to clinical care that would facilitate the diagnosis of their complaints. Thus, they find themselves in the a-diagnostic category, without the endometriosis label. Such forms of stigma act to limit communication through taboos, forcing women to internalize notions such as 'it's a woman's lot to suffer', leading to their increased isolation, and hiding of their suffering. The expected behaviours of not speaking of or complaining of symptoms linked to endometriosis of course means that women stay in the a-diagnostic category longer, as they are then unable to seek help.

II. The Stigma of Menstruation

Menstrual blood can be considered a stigmatizing mark that fits Goffman's three categories of stigma: the stigma related to specific marginalised social groups, the 'blemishes of individual character' and the 'abominations of the body' (Goffman 1963: 4, Johnston-Robledo and Chrisler 2013: 10). Menstrual blood remains symbolic of the 'tribal identity of femaleness'. Its visible presence may be interpreted as an individual character flaw, and menstruation itself may be considered an abomination (Johnston-Robledo and Chrisler 2013: 10).

I have already discussed the history of menstruation and its associated stigma in Chapter 3. Here, I review briefly current concepts of stigma linked to menstruation. Delaney et al. (1988) have pointed out that taboos against menstruation appear in Judeo-Christian scriptures in Leviticus 15:19: 'And if a woman have an issue, and her issue in her flesh be blood, she shall be put apart seven days and whosoever toucheth her shall be unclean until the even' (King James Bible).

The notion of menstruation as pollution is also found in the Koran (Delaney et al. 1988). Historically, in anthropology, menstrual blood has been seen as universally polluting (Douglas 1966). Buckley and Gottlieb (1988) first challenged this idea that menstrual blood was considered polluting universally and its link to women's subordination. In certain cultures, menstrual fluids could be empowering (Hoskins 2002), suggesting that rather than viewing menstrual blood as universally polluting, it may be better to consider the situational specificity of menstrual taboos (Gottlieb 2002).

For example, the social discomfort associated with menstruation is linked to three separate taboos in North American culture (Kissling 1996b). The first, the concealment taboo, refers to the idea that menstruation is something to be ashamed of and that should be hidden (Kissling 1996b). The second, the activity taboo, relates to social restrictions on menstruating women. The third, the communication taboo, alludes to the concept that one should not speak of menstruation (Kissling 1996a).

Laws (1990) presented British 'menstrual etiquette' which she argued involved both concealment and communication taboos within British culture. The concealment taboo meant that menstruation becomes something to be hidden or concealed both orally and visually (Burrows and Johnson 2005, Laws 1990, O'Flynn 2006). Communication taboos limited the ways in which British women were able to speak about menstruation. Thus, women used linguistic strategies such as slang or euphemisms to discuss menstruation in a more comfortable fashion (Kissling 1996b, O'Flynn 2006).

O'Flynn suggested nine perceived social rules related to menstruation in British culture.

> 1. A woman must keep private that she is having a period by wearing suitable clothes and by changing usual activities to prevent any visible evidence of sanitary protection.
> 2. She should avoid any episode of staining or leakage by changing activities, and/or by wearing adequate protection in advance of her period.
> 3. A woman will not explain absence from work or difficulties in carrying out duties by explaining that she is menstruating.
> 4. If a woman feels she must give some explanation, she should say she has stomach cramps or that she is unwell.

> 5. A woman will talk to other women about periods only if she knows the other person well, and if the other woman is judged likely to be understanding or to have helpful information and they are in private.
> 6. A woman may speak to another woman who[m] she does not know well if the alternative is breaking the rule that a period must be kept private.
> 7. In relation to rules 5 and 6 above, non-specific terms or euphemisms such as 'time of the month' are adequate.
> 8. It is particularly important not to talk to men about periods; it is considered appropriate to inform sexual partners about menstruation, but sexual intercourse at this time may be considered distasteful.
> 9. Men and women may be aware that you are having a period, but they will abide by the rules and not mention it (O'Flynn 2006: 952).

The British menstrual etiquette is in direct response to the three types of taboos previously mentioned. Concealment taboos have been long reinforced. Commercials for menstrual products in Britain were prohibited on certain television networks until 1988 (Laws 1990: 46 in O'Keefe 2006: 537). Menstruation was therefore not even referenced for fear of its being both 'uncomfortable' or 'indiscrete' (Laws 1990: 46 in O'Keefe 2006: 537). Menstrual tampons and pads are still designed with the goal of being 'undetectable' and present-day television advertisements of menstrual products avoid any direct mention of periods or menstrual blood using blue liquid instead of anything red to show how efficacious the products are (O'Keefe 2006: 537). Women's behaviour may be self-disciplined through 'fear of social sanctions including derision, ostracism or criticism' (Laws 1990: 43). Negative attitudes towards menstruation remain at the forefront of a situation in which women feel the need to act secretive and feel shame towards their own bodies (Power 1995).

Foucault's theory of discourse as power has been linked to menstrual bodies by Ashley Patterson (2014). For example, she suggested that menstrual concealment is a form of self-policing of women's bodies. For her,

> *[i]t is through the internalization of the panoptical male gaze that young women self-objectify and self-police their bodies, resulting in disciplined attempts to avoid the public spectacle of bleeding femininity (Patterson 2014: 97).*

Consequently, menstrual concealment becomes required behaviour. While Patterson (2014) applied this notion primarily to menstrual concealment of leaks and visible blood, and the resulting self-surveillance that women engage in to hide the bloody

stains, I argue that the stigma linked to menstruation forces women not only to hide the visible signs of a period but also limits communication about menstruation itself. Furthermore, women are not only hiding menstruation from men as Patterson (2014) suggested, but from all others, women included. This suggests that stigma may shape the production of biopower.

Seear (2009b) stated that the menstrual etiquette women adopt may be applied to women with endometriosis. She found that women with endometriosis in Australia expected social sanctions linked to the disclosure of menstruation problems. Women described being reprimanded after discussing menstrual problems, and felt that men often interpreted this 'as an excuse to get out of duties that they believe women owe them' (Seear 2009b: 1124). Women's expected behaviour in the form of menstrual etiquette led them to 'adopt a practice of concealment', a behaviour they engaged in because 'making their menstruation visible' often caused them to be socially ostracized (Seear 2009b: 1124).

Explaining endometriosis on a basic level requires discussing women's menstruation, the uterus, and the idea that cells related to the endometrium are found not only in the uterus but also elsewhere in the body. When discussing the beginning of their endometriosis trajectory, invariably women with endometriosis began by discussing their first period. The specific topic of menstruation was important from the outset.

Examples of communication taboos and stories of experiences where menstruation was not to be spoken of were abundant, and invariably were linked by the women to the reason for getting a late diagnosis. Stacey, the woman speaking below, had symptoms of endometriosis since her first period at age 13. She was not diagnosed until age 32. For her, she could not have known what she experienced was abnormal as she did not understand the normal period.

> *In my family, it wasn't ever to be talked about, it wasn't something we really ever discussed. I always had heavy periods and just thought it was normal.*-SSI

Several women I talked with also spoke of a communication taboo with regards to heavy menstrual flow. However, this seemed related to the visual image of heavy bleeding and perhaps was no longer linked to menstruation itself. Cathy explained that it was not the menstruation itself she was hesitant to discuss, but the presence of blood flooding the bed or the bathroom floor. For her, the blood was not something one talked about because it was a bit 'unseemly'.

For Anna, it was the communication taboo around menstruation as a societal norm that may have contributed to her inability to access a diagnosis or medical care.

> *If just one person had talked about endometriosis at work for example during lunch I might have thought oh I have that, I have that, I have that even I had not wanted to join in the conversation. Or if someone had talked about their periods and those were normal I would have thought oh is my period not normal then. Maybe I would have gone to the GP sooner?* -F

Anna was not just describing her own inability to speak about her condition and menstruation, but also about internalised behaviour in others. The self-disciplinary behaviour that she described ultimately limited her own ability to recognize her ill health and kept her into the a-diagnostic category, which served as a barrier to her future medical treatment.

III. The Stigma of Sex

Literature about stigma linked to sex is limited and is generally focused on topics like homosexuality, HIV and sexually transmitted diseases, and sex work (Herek 2007, Herek 2009, Preston et al 2004, Rushing et al 2005, Cunningham et al 2002). However, Michel Foucault, in his *History of Sexuality Volume I* (Foucault 1976), discussed society's regulation of sexual activity through the Christian church and confession, and the historical connection of homosexuality to mental health and the asylum. He also pointed out how sex was framed in public discourse, arguing that the prudishness of the 17th century

> *was able to ensure that one did not speak of sex, merely the interplay of prohibitions that referred back to one another: instances of muteness which, by dint of saying nothing, imposed silence. Censorship.* (Foucault 1984: 301)

He argued that while this complete silence has now eroded, discussions of sexual topics are now policed and controlled. Discretion is required when sex is discussed between children and their parents or between teachers and students (Foucault 1984:301). This has strengthened the connection between the stigmatizing of sex and the communication taboos at play these days.

Considering sexual relationships as private remains a current concept. A communication taboo still exists where talking about sex is uncomfortable, especially in certain social situations with co-workers, parents, family members or acquaintances. The specifics of sexual intercourse are rarely spoken about outside of the bedroom. A woman would likely only speak to her partner about details of sex such as where, when and in which position pain results. 'Sex and relationships remains a taboo subject between parents and teenage daughters', with 39% of parents still finding it difficult to talk to their daughters about relationships and sex and 15% of parents avoiding 'questions about puberty' (The Daily Telegraph 2009).

Despite its seeming ubiquity as a topic for both discussion and representation online and in the media, sex and its practices remain hidden (Attwood 2009). Within British culture, this is translated as an ambivalence about sex. Sexual innuendo and humour are acceptable, while there remains 'a moralistic censure of explicit discussion of sexuality or sexual practice' (Alldred and David 2007: 2) and associated discomfort, embarrassment, and coyness (Alldred and David 2007).

Talking about endometriosis often required women to discuss dyspareunia (pain during sex). The communication taboo linked to sexual relations was in some ways more prominent than that related to menstruation and childlessness. Within this study, personal sexual activity was the one subject that women with endometriosis preferred not to discuss. Even in the support group, women did not talk much about specifics (positions that were more or less comfortable, for example). In contrast, women in

online support groups who did not know each other personally were more willing to talk about this topic.

Discussions of sexual intercourse were always considered to be delicate in nature and slightly awkward. Individuals participating in such discussions were limited in numbers. Women stated they might talk about such issues with their parents, or family members, but first and foremost with their sexual partners. Discussions with doctors were also considered awkward. Many women with endometriosis described experiences of going to the doctor's office with the intention of asking about sexual issues and being unable to start the conversation.

Many discussions among members of support groups (either online or in person) focused on how to talk to their partners. These either addressed ways of introducing endometriosis to new or potential partners, or manners of discussing changes in physical condition with their current partners. This generally focused on how to tell him (as no-one discussed any female partners) that sexual intercourse hurt more now than before. However, talking to one's partner about pain during intercourse became difficult, as women with endometriosis often felt pressure to have sexual intercourse despite the pain it caused. They also pretended to enjoy the sex. This pressure did come necessarily from their male partners, but was also felt as an unspoken societal expectation.

One example involved a discussion at a support group meeting. We were drinking coffee and tea, eating cake, talking and laughing. The support group resembled young women who were friends having a chat about their lives and partners. Bette stated:

> *I'm not sure if I should tell my boyfriend that it hurts again to have intercourse. I've just been putting up with it, I lock myself in the bathroom afterwards and have a bath which helps a bit but… I don't think he knows. I want the lights off so he won't see the tears.*-F

Some women with endometriosis also felt pressure to ensure that their partners enjoyed the sex despite the pain.

> *And even relationship-wise you know it's painful. If we sleep together, I bleed. Afterwards you know I can be in pain for a couple of days. So that's quite difficult as well. It can't be great for him, that you know yeah I'll sleep with you but actually I'll be in agony for afterwards it must make them feel great.*-SSI

During the support group meeting, Natalie talked of her ex-boyfriend who she believed ended the relationship in large part because of endometriosis. This was related to a fairly common fear of women with endometriosis — that their partners would leave them because of decreased sexual activity. This worry was echoed by Shelley, who said: *'We just don't have sexual intercourse anymore – it's a miracle we're still together'*-SSI.

Some women also worried that the inability to have sex affected their womanhood. It was not uncommon to hear '*it challenges my femininity* '-SSI. The inability to have sex was in some way felt as a failure to fulfil their role as a wife or partner. This was reflected in the comments of Lucy who stated that: '*it concerns me that I will not be able to be that person to them having sex and stuff*'-SSI.[10]

Women with endometriosis were also concerned about how future sexual partners might react to the news of pain during sex and the possible inability to have sexual intercourse.

> *And I know a friend of mine [who] has got endometriosis finds it very difficult now cause she's single and she worries about what's gonna happen if I have a relationship and about kids and all this that and the other.*-SSI

Therefore, the discussion of sexual intercourse and fertility became interconnected. The worry that she will be unable to have sexual intercourse without feeling pain became linked to the fear of not having children.

The communication taboos related to sex meant that women with endometriosis struggled to talk with doctors about their dyspareunia and limited their access to care and potential treatment for this problem. With pain during sex often aggravated by earlier painful sexual (heterosexual) encounters (Fritzer 2013), this inability to access

[10] The impact of endometriosis on femininity is discussed further by Denny and Mann (2007).

care itself worsened the dyspareunia women experienced. Women self-discipline through 'continu[ing] to have sexual intercourse despite pain and discomfort, … pretend[ing]… not to feel pain or discomfort, or feign[ing] enjoyment … as part of … striving to be an ideal woman' (Elmerstig 2008, 360). Unfortunately, women with endometriosis have not escaped this pressure; in Austria women with the disease have been found to 'sacrifice their own pleasure and had sexual intercourse despite pain with the focus on the partner's pleasure instead of themselves' (Fritzer 2013: 395). Thus, the influence related stigma of sex is not limited to communication taboos but involves expectations of women's roles as sexual partners and potential mothers (as I will address in the next section).

IV. The Stigma of Childlessness

Western society has been characterized as pronatalist, a society that is 'pro-birth' and where parenthood is emphasized (Miall 1985). Two fertility norms are that 'married couples reproduce', and that 'married couples should want to reproduce' (Veevers 1980:3 in Miall, 1985:384). Childlessness goes against these norms. It is considered 'a form of deviant behavior in that it is statistically unusual and violates prevailing norms of acceptable conduct' (Miall 1985:384). Such ideology places childlessness firmly in contrast to femininity and the definition of what it means to be a woman:

> Pronatalist cultural discourses have contextualized the meaning of the term 'woman' around the inevitability of a desire for motherhood, and the centrality of motherhood to understandings of feminine identity (Gillespie 2001:142).

If a woman's purpose is to become a mother, and she cannot fulfill that role, then is she still a woman? Childlessness represents what Gillepsie called 'failed femininity' in contrast to 'normal' womanhood constructed as 'heterosexual, fertile, life-giving, selfless and fecund' (Gillespie 2001:142).

The literature makes a distinction between voluntary childlessness or childlessness by choice, and involuntary childlessness, or childlessness related to infertility or subfecundity (Miall 1986, Gillespie 1999). Women who are unable to have children are

seen as people to be pitied and to be supported in their moment of need (Gillespie 2000). In contrast, women who choose not to have children are seen as selfish and unfeminine (Gillespie 2000). Both forms of childlessness are viewed as stigmatizing and often result in isolation. This may relate to the previously stated notion of womanhood as inextricably linked to motherhood. It has been debated whether the stigma attached to infertility relates to the association with a physical deformity or to "deviation from group identity" (Whiteford and Gonzalez 1995). While Miall (1985) suggests that infertility is more likely associated with a physical deformity, Whiteford and Gonzalez speculate that 'the stigma attached to infertility rests not on the perceptions of a physical deformity, but on the sense of having broken a group norm' (Whiteford and Gonzalez 1995:29). They argue that the only visible sign of infertility is the lack of children. Involuntary childlessness is nevertheless still associated with the notion of the 'failed body'. Medical discourses link the term infertility to notions of disease and illness. Thus, infertility should be diagnosed and treated, while also becoming a source of stigma for the childless woman (Gillespie 2000).

The inability to become a mother has become linked with western biomedical notions of psychological or physical illness. Involuntary childlessness is associated with the notion of the 'failed body', and therefore with the medical discourses associated with the term infertility.

> The physical inability to have children, or the 'failed body' as associated with involuntary childlessness, is constructed as infertility, synonymous with notions of illness and disease. Infertility is dominated by medical discourses associated with abnormality, treatment and cure. Once diagnosed, the usual course of action is medicalization and treatment in the hope of bringing about a pregnancy and the birth of a child (Gillespie 2000: 225).

Whiteford and Gonzalez (1995) suggested the medicalization of infertility was a relatively recent phenomenon. It was not until the 1950s that infertility was considered of medical/physical origin. Until this point, infertility was seen as related to emotional causes. This was soon followed by the first development of medical drugs that helped 'control ovulatory cycles' and the laparoscopy (keyhole surgery) that allowed the visualisation of women's gynaecologic organs (Whiteford and Gonzalez 1995, Greil 1991).

Such notions of motherhood and its connection to biopower have been addressed often and in many different contexts. Foucault wrote about sexuality and discussed the expectation that women be mothers. They should put children or potential children above their own interests (Foucault 1976). Modern examples have been provided in various cultural contexts including Italy (Marchesi 2012), Poland (Mishtal 2012) and Pakistan (Varley 2012). Others have written about the role of IVF and new reproductive technologies as forms of biopower (Larsen 2015, Sawicki 1991), with connections between reproductive loss and biopower, for example (Martel 2014). Thus, the stigma of childlessness may be connected to the exercise of biopower. Women with endometriosis change their behaviour. They follow the communication taboos that impose silence about childlessness, but may still preserve their own fertility despite not wanting children.

The stigma that women with endometriosis discuss with relation to childlessness is interestingly linked to both involuntary and voluntary childlessness. While some women with endometriosis cannot have children, they may still want to. Other women do not want children but feel that their treatment has been in large part linked to the assumption that they will want children at some point. Even if they have decided not to have children now, it is assumed by medical professionals that they may change their minds.

Women felt that medical professionals took their symptoms more seriously when they were looking to get pregnant. Patricia said '*it was not until I wanted to have children that they took me seriously and really investigated the problem*'-SSI. Women with endometriosis also thought that medical professionals did not accept their decision to not have children. Here, the women believed that medical decisions that could have improved their quality of life were not taken. This was done to preserve their option of having children, even though they had no intention starting a family. The women felt the medical professionals were expecting them to change their minds, assuming that it

was impossible for a woman not to want children. This was a form of disciplinary power exerted through medical professionals on these women.

Women with endometriosis were unable to discuss this involuntary childlessness with many people. Generally, it seemed a topic they reserved for their partners and in special cases their mothers. Women spoke of their extended families' knowing about the involuntary childlessness but usually thought that the family was less than understanding and just put pressure on the couple. Melissa stated that her extended family would say:

> *Oh you'll have a kid, it'll be fine and this that and the other and were dismissing anything that* John (her husband) *or I said. And that felt a bit like do they not believe me.*-SSI

However, it is unclear whether this inability to speak of infertility was completely a matter of stigma. Women with endometriosis also discussed grief, specifically in relation to infertility. The topic of infertility was seen as personal, and partly due to emotional loss.

> *It's (endometriosis) made me more careful about who I would have a relationship with and what kind of person and so my husband now is fantastic, you know supportive. I don't think they ever really get it. It's difficult cause they can't see and you get used to managing your pain so unless it's really bad and you kind of go aaah I try and get on with it but he's really good whereas I've had other relationships where at what point you tell somebody you've got something like this? Do you not tell them? You know do you go with somebody that wants children because that's the kind of person I would like or do you go with somebody that doesn't want children because you might not be able to give them children so it's always the thing isn't it?*-SSI

Even within online groups it became controversial whether one should discuss successes with fertility, pregnancy problems related to endometriosis, or difficulties with children. Some women believed this type of discussion did not belong in a forum about endometriosis. Instead, any mention of the word 'pregnancy', or 'children' was considered by some to be severely upsetting because of the grief felt by some members of the group. Some stated that in writing posts mentioning pregnancy or children one should include a trigger warning, something increasingly used when discussing rape, sexual abuse, or eating disorders. A trigger warning of course is a version of a

communication taboo where one must first warn before broaching a particular topic. Thus, women were still self-disciplining meaning they restricted when and with whom they communicated on these topics. In addition, the need to be a mother made women feel pressured, whether they wanted to have children and were unable to or whether they had chosen to not have children.

However, I emphasize that stigma related to childlessness ultimately limited women's access to care and control over their own bodies. The women were limited to certain treatments based on the 'potential reproductive career' they could have, whether they saw that as a plan for their lives or not. Potential reproduction takes precedence over any other outcome in endometriosis treatment. At the same time, there are other women who speak of the involuntary childlessness associated with endometriosis and the surveillance by family members and others when they do not produce children quickly enough.

V. Suffering in Silence

> *I want to scream..but the only word that exists is..SILENCE. This is one artwork for my Project on "The Heart's Silence" an exhibition of charities around the world to raise awareness of the research and information on endometriosis.*- (Talia) -O

Women with endometriosis often discussed their feeling of 'suffering in silence', which they believed was a direct result of the many communication taboos related to endometriosis. The silence is what remains, what exists and what is dominant. As Talia explains above, she wants to scream but only quiet emerges. The irony of capitalising the word silence, which online now often means shouting or screaming, is not lost here. It is particularly evident when her comment is about Figure 7.1 which is named 'The Heart's Silence'. This image of the woman screaming makes the suffering and the accompanying noise almost palpable. Her hands appear tied together as if she is unable to break out from whatever is restraining her in the metaphorical prison.

Figure 7.1
'The Heart's Silence'

While Talia wants to scream, it is impossible to capture her emotions verbally. Instead, only silence comes out of her mouth. This inability to express her emotions and to feel her voice is heard represents a common feeling amongst women with endometriosis, even during a day out shopping with the family. Sally explains:

> *If you're out with them (family) for the day for example going shopping I can't walk around as much as everyone else can do. So you can kind of try and hint don't you that actually I might need to go and sit down, I'm getting a bit tired. But unless you quite forcefully say I can't do this anymore and worry about upsetting other people, you make yourself do stuff I think, don't you, when actually inside you're absolutely dying. You think: I know I'm going to be really ill here.*-I

This is represented in Figure 7.2 showing a woman evidently crying while stating she is fine. She cannot share her suffering and struggle with others. As a result, she suffers silently, and there is no one to bear witness to her suffering.

Figure 7.2
Image illustrating the inability to share her struggle with others.

Figure 7.3 portrays a woman with sad eyes who has a death's head hawk moth in the place of her mouth. She has a gag on her mouth, albeit one that appears to look beautiful and suggests softness and femininity. But the death's head hawk moth, so named because of dorsal markings that resemble a human skull and crossbones, has long been considered 'an omen of evil or a forerunner of death' (Cherry 2011: 82). In addition, the woman is dressed primarily in black as if she is marking a traumatic event or the loss of someone. The symbolisms of death and mourning here are quite apparent. She may be symbolizing her loss of speech or her enforced silence. We know, of course, that the presence of the moth stops her from telling us about her story. For Laura, the silence represents the experience of endometriosis, with the ensuing feeling of isolation.

> *I know for a long time I suffered in silence with #endometriosis and only those closest to me knowing the pain I lived with.*-O

Jessica suggests that the silence is in part the result of having no name to give to this thing that causes her pain.

> *[T]his is how I felt when I started my period at the age of 12 and no one knew, not even me I thought there was just something wrong with me and how I handled pain*.-O

She knew there was something wrong with her but was unable to verbalize her experience because her suffering had not yet been given a label. For Elaine, Figure 7.3 reminds her of her inability to explain her experience of endometriosis to others. She says:

> *[I] still feel like this to today becuz no one around knows truly how [I] felt going through this.*-O

The quiet has everything to do with her feeling that others are unaware of what she has gone through. And Figure 7.3 illustrates well the expression of her isolation.

Figure 7.3
'Silence' (Art Print by Ana Bagayan).

This feeling of 'suffering in silence' was linked to the idea that endometriosis is an unimportant or dismissed disease. Women with endometriosis also suggested that the silent suffering and the dismissiveness occurred, in part, because endometriosis is a disease of women. The women discussed the interaction between this gendered condition and stigma, which resulted in this solitary and silent suffering. As my research participants frequently stated: *'it makes you feel lonely doesn't it?'* and *'If you don't have [endometriosis], how can you understand? You can't can you?'*(-SSI).

VI. It's a Woman's Lot to Suffer

Time and again in my discussions with women in my study, the idea came up that endometriosis is highly stigmatizing and gendered. It seemed a common experience internalized by many women that 'it's a woman's lot to suffer'. Many of them stated that as teenagers they learned this from family members or health care personnel, who were generally the only people with whom they discussed menstruation. Statements like: *'because you're a woman you're just meant to put up with it'*(-SSI) were common in my interviews. This statement was applied most often to pain related to menstruation and linked to the notion that in women with endometriosis, symptoms were often dismissed both by the medical community and by others such as family members and school nurses. This contributed to women's movement into the a-diagnostic category.

Women with endometriosis often stated that when they were teens their symptoms were dismissed as either '*Just Period Pain*' or '*bowel cramps'*.

> *I have had symptoms of endometriosis since my late teens. However, I did not know they were endometriosis symptoms. I told my mum about them and she said they were probably 'bowel cramps'.*-Q

Women also noted that 'teenage menstruation' was something that had yet to settle down. Several of them reported being told, *'oh it's her age it'll settle down'*-Q. The pain associated with menstruation in the teenager was seen as normal, recalling the notion encountered in Chapter 3 that normal menstruation is abnormally painful. Ultimately, the women reported that the difference between endometriosis pain and menstrual pain became blurred. One informant stated that she had many times been told *'You've got endometriosis. What's that? So Just period pain?'*-SSI. Because it was indistinguishable from 'normal' period pain, endometriosis became the ultimate 'normal' state of a 'woman's lot to suffer'. This idea became so ingrained that even *'GPs think period pain is normal'*-Q.

These 'historical' notions live on in the present day, impacting the a-diagnostic category and the struggle for a diagnosis of endometriosis. Women learn to internalise the notion that they are just meant to suffer. This dismissal of endometriosis symptoms into the a-

diagnostic category ultimately reinforced the idea that 'It's a Woman's Lot to Suffer' and led many women with endometriosis to believe that what they were experiencing was 'normal'.

> *In my teens it was very bad- I missed out on quite a lot because I was laid up suffering with it. As I got older I just learned to cope, really – I believed there would never be any help forthcoming, that it was 'normal' for some women to go through this, and that I just had to deal with it.*-Q

Thus, the self-disciplinary behaviour where one cannot ask for help as it would not come, and the notion of having to just 'deal with it' of course reinforced the communication taboos here. The expected behaviour that women not complain, but somehow learn to cope suggests that women were discouraged from seeking help from medical professionals or others (mothers and school nurses, for example, as seen in Chapter 4).

Acceptance of the suffering was also applied to the sexual realm. As discussed previously, women with endometriosis felt they should not complain if they had pain during sexual intercourse. They stated that it was a task they were meant to accomplish regardless of the pain involved. If they were unable to have sex, they were somehow deficient.

'It's a Woman's Lot to Suffer' encompasses all aspects of endometriosis as illustrated in Figure 7.4 below.

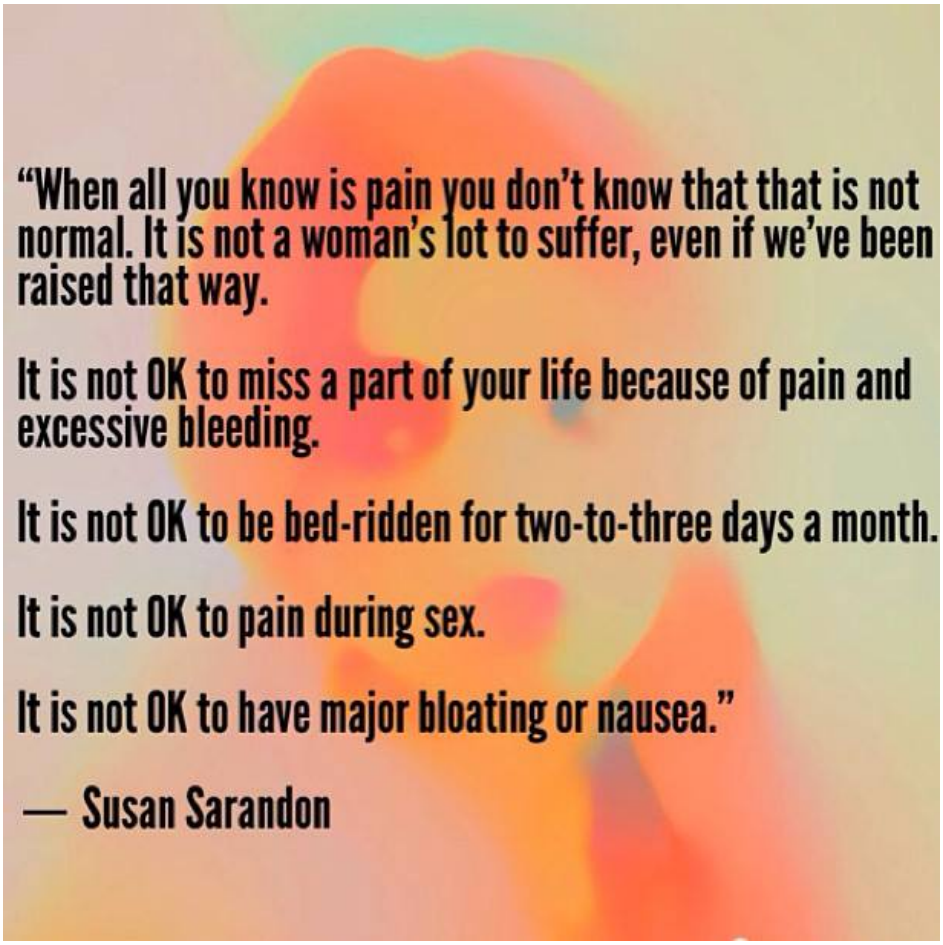


Figure 7.4

Poem by Susan Sarandon summarizing suffering in endometriosis.

VII. Mask of Health

In response to the stigma they experienced and the associated internalised communication taboos around endometriosis, women often mentioned the need to hide their condition. They discussed tools and methods they used to 'pass' as healthy. They employed this 'mask of health' on a daily basis and with most people. They recognized they needed to use the "mask of health' to go through life. They took it off when they came home and stretched out on the couch with the hot-water bottle. Many women with endometriosis used this mask as a mechanism for accomplishing daily tasks and avoiding the communication taboos I previously discussed.

In support group meetings, women with endometriosis talked about 'putting on a face' to go out every day. They used make-up to hide their paleness or tiredness.

> *We put on a brave face before we go out don't we? When we are at home we lie down on the couch with the hot water bottle on and don't move unless absolutely necessary.*-F

> *I always look pale if I don't put on make-up. I won't go out of the house without putting on make-up. Otherwise I might have people asking me if I am feeling ok.* -F

Putting on a brave face became a necessity that the women imposed on themselves. The self-disciplinary behaviour was to camouflage their suffering with makeup, to hide the pain daily, and to present to the outside world the image of a healthy woman.

Figure 7.5
An illustration of 'sitting strong, but curled in pain on the inside'.

Figure 7.5 represents a young woman sitting, while another superimposed image shows her doubled over, probably in pain. In response to Figure 7.5, several of my research participants stated that this resonated strongly with them.

This is what we do every day isn't it? We act like we are not in pain when we really are don't we? We feel bent over in pain like that but we cannot show it.-F

In addition, Elisabeth wrote: '*This describes us perfectly. Sitting strong, but curled up in pain on the inside.*-O' Judith stated that this was '*Eerily familiar, also reminds me of how good we get at hiding our pain*.-O' In the support group, women with endometriosis also discussed the notion of '*putting on a smile*-F' before going out the door. While this is similar to putting on a brave face, it adds an element: part of the 'mask of health' seems to involve a portrayal of happiness in the form of a smile.

'Smile through the tears'

Figure 7.6
'Smile through the tears'.

'*Smile through the tears: we have to act like everything is ok*', Figure 7.6 tells us. We imagine the woman with cheeks still wet saying this to us in a voice that cracks. Even as she is crying, she must fight to keep the 'mask of health' intact. Maintaining the 'mask of health' was considered a show of strength. Women with endometriosis often felt it necessary to hide their true physical and mental state. Putting on a strong face allows the woman in the picture to hide the illness from others. She is strong if she manages to keep hidden the emotions associated with endometriosis.

I mean I work within family planning and contraception services and things. And I think people would assume that the people would be more sympathetic but they're dealing with it all the time every day. So really I can't offload at work or talk about it particularly. You just have to put a brave face on and get on with it. Whereas a lot of the times, you feel like you absolutely can't make it through the day, but can't be off sick. So really I work full time but actually could, really could do with not working full time. I struggle.-SSI

Figure 7.7
Image of a woman with a strong face, with tears and pain in her eyes.

Barbara, the woman who posted Figure 7.7, asked other women on the website '*what do you see in this? #endometriosis*'. In response, Mandy noted: '*I see a woman putting on a strong face yet inside she's crying'*. Catherine said: '*Sorry to be quite bleak, but I stupidly forgot to go get my new zolodex injection and in agony. I see blood sweat and tears with a brave face*. Deborah states that she sees: '*blood & tissue flowing while she keeps calm on the outside, while sad to rage on the inside'*. Finally Kelly emphasized:

Oh!! This picture is beautiful!!! I recognize the pain in her eyes, yet she puts on the strong face...I can really feel her pain...I have to share this...-O

The common understanding seemed to be that this image represented a woman putting on a 'strong face' while crying internally. The women felt that this represented strength. Another woman, Frankie, noted that

> *I don't let anybody know I have the illness. Work is the safest place I've been with [endo]. The majority of the time I can hide it – they think I'm strong.*-SSI

She insisted on hiding endometriosis from everyone. For her the 'mask of health' was vital. It was through maintaining the appearance of physical health and of happiness that she was able to show strength. Not maintaining this 'mask of health' was understood as fundamentally giving in to endometriosis and therefore became a sign of weakness, often leading to feelings of guilt. When they were unable to do these tasks as expected, they thought they had failed and had given in to the 'truth', that of the illness and its limitations.

> *It was awful as it turned out I decided to leave because every time I went back in I felt guilty because I'd been off people would talk about you in offices so you get all this ooo she's off again ooo and all this sort of thing I was surrounded by all these comments and people didn't understand and it wasn't their fault but they weren't very nice and the bosses and stuff didn't help and it didn't help that this second or third report it was the third one wasn't very good and I had to appeal against that on top of everything else and I felt like all the time it's been a battle constantly with stuff like that.*-SSI

This 'mask of health' therefore became not only an internalized, self-disciplinary form of behaviour due to stigma, but also contributed to increased responsibility of the women to somehow control their bodies not unlike what Martin (1987) described.

VIII. Endometriosis as Invisible and Unseen

The invisibility of endometriosis in part relates to the fact that the disease cannot outwardly be seen, but also may stem from the various stigmas previously discussed in this chapter. As endometriosis was unseen, it was easy to hide. Candice stated that '*[endo] is not something you can see. I try to hide it from the kids'*-I. She used the invisibility of endometriosis in addition to the 'mask of health.'

Figure 7.8 alludes to this same invisibility. The woman who posted it joked that it is 'an iceberg metaphor'. But in reality, she captured the essential notion that much of endometriosis is below the body surface and minimally visible to the outside world.

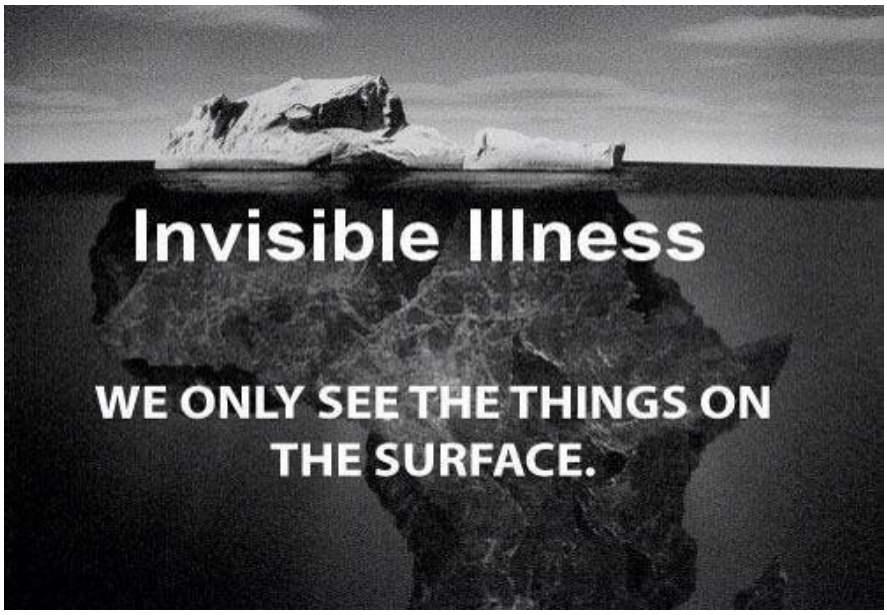


Figure 7.8
The iceberg metaphor of endometriosis.

The invisibility means that women with endometriosis feel that others cannot see their condition, which may be beneficial if they wish to hide their suffering. On the other hand, the invisibility of the illness may make it easier for others to ignore those who are experiencing the suffering. Feeling ignored may result in women with endometriosis feeling that they are 'suffering in silence'. Thus their own internalisations of the stigmas around endometriosis, and their own self-disciplinary behaviour to adopt the mask or health, or communication taboos, or not seek help because it's a woman's lot to suffer may all contribute to endometriosis being an unseen and invisible disease.

IX. Resistance to Stigma

Women with endometriosis not only spoke specifically about experiences of stigma related to these three physical symptoms of endometriosis, but went further to link such taboos to women's bodies more generally. In speaking of being unable to discuss endometriosis, the phrase '*It's not something you talk about is it*?' frequently came up. The communication taboo that they expressed is one that they feel is inescapably linked to gendered notions of endometriosis as '*a woman's disease'* or being about *'women's bits*', terms I found frequently in my interviews and online. For many women, it was not only the link to menstruation, sex, or childlessness that led to their experiences of stigma, but instead women's bodies were not to be spoken of, or at least those organs that labelled women as different or distinct from men were to be hidden.

Phoebe for example explained:

> *I'm not a militant feminist by nature, but I do feel that being a 'women's problem' it has become a bit invisible as a result. Part of that is our own fault – either not wanting to talk about it, or trying it then taking no for an answer.*-Q

For her, endometriosis had become invisible because of the stigma associated with its status as a '*woman's problem'*. Not only was endometriosis silenced, it also remained unseen, both a cause and a consequence of the taboos surrounding women's bodies more generally. When women did speak of such notions, they often did so in in an effort to move forward and improve a deeply stigmatizing situation. Even Phoebe considered her own role in reinforcing the communication taboo around endometriosis.

Figure 7.9 addresses this notion that women's bodies are not to be spoken of, while suggesting resistance to this idea. The latter appeared primarily online, perhaps because of stronger links with biosociality and the endometriosis movement[11]. In Figure 7.9, the word '*vagina*' is used to illustrate the resistance effort. This textual image addresses the stigmatized associations that relate to the word vagina. Janet, the woman who posted

[11] I discuss the endometriosis movement in more detail in Chapter 9.

this image, believes it to be related to endometriosis as she writes hashtag endometriosis.

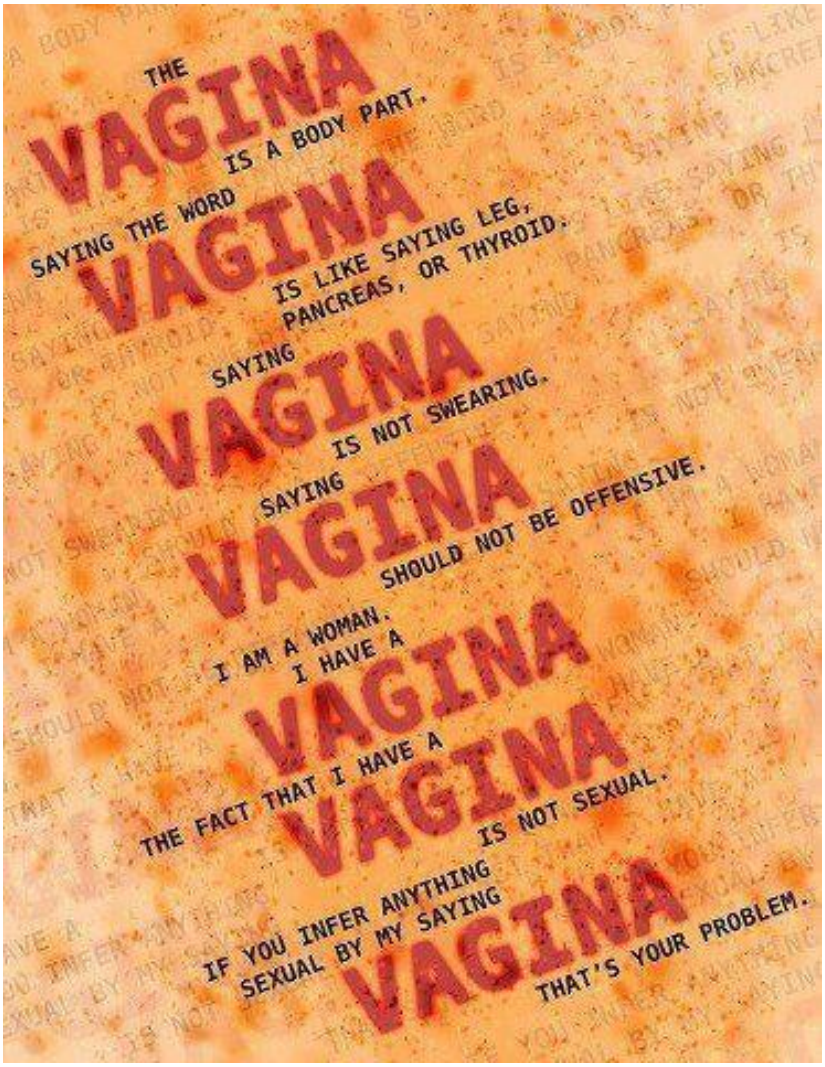


Figure 7.9
Poster challenging the stigma of the word vagina.

We are taught young not to say vagina or don't talk about anything that may happen to a woman with her reproduction organs.... says Nancy in response to Figure 7.9.

Although the image in Figure 7.10 seems unrelated to endometriosis, Amelia, the woman who posted the Figure, linked it to the disease. The Figure shows a woman wearing a headscarf and holding a can of soda.

Figure 7.10
The old world taboo in a new world.

Amelia provided the following explanatory comment:

> *#endometriosis This is a clever picture that shows that beautiful quiet strength, look closely. In it I also see a woman living between two worlds, old and new. I think the taboo of talking about periods and other female reproductive problems is an example of everyone of us living between old and new worlds. It is still not socially acceptable for us to talk about a prevalent problem but in today's world if we want awareness and answers we need to talk about it. We need to break out of the limbo stuck between the old and new.* -O

This picture certainly may be seen as covering up the woman's body. But the commentator also sees the possibility of resistance here, arguing that the Figure reflects an inadequacy of communication ascribed to the difference between an 'old' and a 'new' world, with a suggestion that progress needs to be made or at least that we are not as far advanced as we may think.

It was also quite common for women to express a feeling their voices were being silenced. The communication taboos seemed directed at women either through their

voices or their bodies. Figure 7.11 represents a female doll with her mouth duct-taped in the shape of an X. Next to the doll is written '*The Voice of Woman Is Obscene*'.

Figure 7.11
The voice of a woman is obscene.

Lily, who posted this, stated:

> *Last week was a hard week for me, #endometriosis, processing a few things for myself. One of the issues that popped into my head was gender roles. I found this picture on a blog and it started me thinking about women, or silence or limited ability to speak openly about issues society sees as taboo such as menstrual health. We need to talk about it, why should we lower our voices when we talk about our bodies.*-O

Charlotte responded by saying*: 'So true. And why are we as women left feeling inferior when we have issues?*-O' Ella asked: '*Is it still a 'man's world' we live in? Sometimes it seems that way.*-O' This idea that the taboos relating to endometriosis are in large part associated with gender seems to be shared by many women with endometriosis. For them, women remain inferior. Many women said if it was a disease that affected men then it would be taken seriously.

Helen also confirmed that endometriosis' link to a body that bleeds and cycles is what allows it to remain surrounded by silence. She said:

> *I never understood why we should be silent about menstrual or sexual health as it pertains to women. Nobody understands conditions like endo because of this great silence and taboo against it. It's almost like even in our "advanced" and "modern" world, men are still afraid of us because they still don't understand why we have cycles and bleed and then stop for no reason other than it's a natural process. And the women who have a menstrual health problem are chastised by those who choose to believe that all periods are created equal. Probably more of an ignorance than an intentional snub, but ignorance can be fixed by education.*-O

For her, our '*modern*' world is in fact not so advanced. The taboo remains because 'men are still afraid' of women and their unexplained menstrual cycles and because of the belief that '*all periods are created equal*'-O. This then impacts on women who have menstrual health problems.

Pamela linked the communication taboos directly to the female body.

> *In feminist, or more relevant, psychoanalytic terms ... the female biology strikes inherent fear to patriarchal norms .... the boundaries society abides by are gender biased and 'woman's issues' simply do not comfortably fit within that boundary ..... when I talk about endo I find a real wall of taboo is formed as I talk about reproductive parts etc THEN as soon as I say it can also affect lungs/eyes/kidneys/brain people find it more accessible and 'serious; It seems to me that the only way to break these taboo walls is to talk, talk, talk and keep on talking until we are heard .... it will happen as long as we don't give up.*-O

For her, it is the woman's body that causes fear. Endometriosis when thought of only as a disease of women's '*reproductive parts*' does not fit within acceptable societal boundaries, and therefore becomes a taboo subject. Endometriosis only becomes a '*serious*' and '*accessible*' condition when she moves away from the link to women's genitalia and on to other parts of the body such as lungs or brain.

For both women, the solution to this taboo, this wall of silence, is education and to 'talk, talk, talk'. This concept of 'mentionism' or 'mentionitis,' the idea that women should mention endometriosis more and frequently to increase knowledge and awareness of the disease becomes very important within the endometriosis awareness movement

(Hummelshoj 2014). For more discussion on this and other concepts relating to the endometriosis movement, please see Chapter 9.

While much of the discussion about trying to move past stigmatized notions of endometriosis took place online, it also occurred in support group meetings where women with endometriosis described an evolution regarding their feelings towards the communication taboo they had all described. Whereas the stories of communication taboo were mostly placed in the past, the women discussed having largely moved past this taboo. For example, Anna explained:

> *I have no 'fear' anymore. If people are uncomfortable I don't care anymore. I don't want anyone else to have to go through what I went through. So I talk about it. If I tell just one person about endometriosis then maybe that knowledge will trickle down.* -F

The biosociality involved in both of these types of interactions (be they online or in support groups) appears to allow for a movement of resistance against this internalised stigma and the associated self-disciplinary behaviour. But now, with this new-found freedom from self-regulation, comes another expectation or responsibility to help free others from the binds of communication taboos. This responsibility should facilitate an earlier escape from the a-diagnostic category and earlier diagnosis of endometriosis.

X. Doctors, Endometriosis, and Stigma

While women with endometriosis associated their disease with stigma, medical professionals did not even comment on it. Doctors discussed stigma in relation to patients' disclosure of information about sexual issues. For example, one gynaecologist suggested that patients found it difficult to speak with doctors about sexual matters. Gynaecologists, pain management specialists, and psychologists all felt that patients did not openly discuss previous experiences of sexual abuse, which they saw as potentially linked to chronic pelvic pain. Therefore, overall medical professionals in this study spoke only of sexual stigma in relation to the clinic visit and did not acknowledge the stigma patients may face outside of the doctor-patient interaction.

XI. Conclusion

In this chapter, I focussed on women with endometriosis and their experiences with stigma, and on the subsequent internalisation of notions such as 'it's a woman's lot to suffer'. Stigma causes women to self-discipline their behaviour to fall in line with expected roles, such as not complaining, 'putting on a mask of health', or continuing to have sexual relations despite pain. Women with endometriosis reported limiting the information they shared about their condition and with whom. They felt an obligation to hide their illness and decided they must 'suffer in silence'. This caused them to feel isolated and that they should pretend to be healthy.

As they felt unable to discuss specific aspects of endometriosis effectively, they also believed that they were required to hide the illness and to put on what I have called a 'mask of health'. The notion of endometriosis as an 'invisible' or 'unseen' illness was important. The invisibility of the disease made it easier for the women with endometriosis to hide their illness from the outside world. But, invisibility carried both positive and negative aspects. As others could not see that they were ill, women with endometriosis concluded that they were expected to 'suffer in silence', which increased their isolation from friends and family. This isolation seemed to enhance their view that endometriosis was dismissed as unimportant. That idea in turn reinforced the notion that they were somehow assigned to carry the burden of suffering.

For women with endometriosis, this self-regulation found its way into the workplace, the doctor's office, the school nurse's offices and even home, shaping the production of biopower in these spaces. Women hesitated to discuss endometriosis with their doctors (Cox et al 2003b), in their work environments (Denny 2004), and with other women. This self-disciplining because of menstrual stigma meant that problems around menstruation were silenced. They could not be spoken of in the work-place. Absences related to menstruation were explained through allusions to being generally unwell or feeling abdominal discomfort (O'Flynn 2006), something that extends to other spaces of course. In addition, menstruation was polluting and dirty. This secrecy around periods has been reported in multi-ethnic populations with endometriosis (Denny et al 2011),

suggesting even greater self-regulatory behaviour in these communities. Such forms of self-disciplining have practical consequences. For example, women with endometriosis struggled to acknowledge their own menstrual abnormalities and therefore were at a loss for words when called upon to discuss these matters with their doctors. This verbal hesitancy not only limited their potential access to care and treatment for endometriosis but reinforced notions of menstruation as normally painful. This in turn enhanced their inclusion in the a-diagnostic category.

The self-disciplinary behaviour also had a direct impact on women's symptoms of pain during sex, with their feeling pressure to have sex despite pain. The inability to speak out about such issues made access to medical care difficult. Hence, improvement in pain symptoms through changing positions, increasing lubrication or other physical interventions remained unlikely as an outcome as their partner may not even know about the problem. In a situation where expectations of pain during sex have been shown to increase dyspareunia because of increased tension (Fritzer et al 2013), such self-disciplinary behaviour only worsened the symptoms that were at the heart of the communication taboo in the first place.

Women with endometriosis experienced stigma around both involuntary and voluntary childlessness. Denny et al (2011) found concerns about the acceptability of childlessness prominent in women with endometriosis from multi-ethnic communities in the UK. I suspect this concern is common across ethnic communities. Here, disciplinary power linked to childlessness was exerted through family members and medical professionals such that women felt they could not speak about childlessness. They were forced into medical decisions that may not have been right for them. They had to make a choice between fertility and functionality. This is the case when they had to consider a hysterectomy to improve endometriosis symptoms.

These findings also had implications related to the women's access to medical care. They believed that menstruation was a taboo subject that affected how long it took them to receive a diagnosis. They also concluded that these same stigmatising elements of

endometriosis limited what they could say to the medical professionals, and what kind of treatment they could choose. So even when they found themselves in the consultation room, self-disciplinary behaviour linked to stigma still limited their access to potential care, especially with regards to childlessness and dyspareunia (pain during sex).

It is through biosociality that women with endometriosis began to sever the bonds of stigma around endometriosis. They saw that women's bodies were seen as ultimately flawed, things to be silenced and hidden. Thus, online especially, they called for people to have 'mentionitis', to talk about endometriosis. It is through this form of resistance that the women tried to distance themselves from the idea that a woman's body is something to be controlled, disciplined, and hidden. Medical professionals did not acknowledge how stigma impacted on the clinic visit, despite the disease's link to menstruation, sexuality, and childlessness. So the enactment itself of endometriosis as a hidden, invisible, and unseen illness was the very thing that placed women into the a-diagnostic category. At the same time, it catalysed women's quests for the singular label, the golden chalice expected to free them from the very expectations imposed on the female, endometriosis body.

CHAPTER 8

Adapting to the Failed Body

I. Introduction

The kinds of intense feelings of stigma I presented in the previous chapter were examples of enactments both inside and outside the biomedical clinic. They also were linked to ideas of bodily failure. In this chapter, I concentrate on a unique phenomenon that Mol (2002) has highlighted for us: that people with chronic disease are able to talk in a unique fashion about their disease bodies, their impaired bodies, and bodies with which they must contend in leading their daily lives. This leads us to the production of understandings and enactments of the endometriosis 'body' outside of biomedicine looking at the new 'failed body' and how it affects women's experiences of disease. Emily Martin (1987) highlighted this concept in her discussion of women's use of vocabulary around menstruation and childbirth.

Enactments in non-biomedical spaces contrast quite sharply with biomedical notions of endometriosis, particularly when it comes to visual representations of the disease and associated pain. Women's enactments, particularly where notions of endometriosis are linked to issues around mental health, sharply contrast medical notions of endometriosis as distinct from psychological issues. Thus, psychological notions as separate from endometriosis often predominate in clinical practice and partly account for women finding themselves back in the a-diagnostic category without their endometriosis label.

Mol (2002) reminded us that enactments of disease may take place outside of biomedicine and the clinic. Mol thoughtfully made this distinction in emphasizing that physicians often engage in the talk of diseased bodies (other people's bodies) through their technical language, while patients talk about disease and its effect on their lives. The reality is that enactments of endometriosis also occur outside of the clinic and sometimes are at odds with enactments in medical settings. Yet, it is precisely because of their separateness from biomedicine that non-biomedical enactments need to be highlighted to healthcare practitioners working within biomedicine and acknowledged within the clinic visit itself, something Mol (2002) discussed.

I focus attention on the enactments of endometriosis and on the understandings of the endometriosed body outside of biomedical systems. This step, as noted by Mol (2002), naturally prioritizes the patients' voices and is inherently ethnographic. Women with endometriosis bear witness to this transitional process in which their bodies undergo transformation from healthy to diseased. It is this new body, a 'failed body' that many women reject as not their own.

I provide visual representations and images that women posted online to represent the new 'failed body'. Women felt that what were previously easy tasks became difficult. They spoke of the inability to fulfil their dreams and of new difficulties in interacting with family members, friends, and co-workers. I consider their emotional burden attached to having this new body. Women reported feeling overwhelmed, down, with loss of self-esteem, and grief coming to terms with the new endometriosed body. Finally, I look at how women envisaged this change. Some women spoke of the way in which they were in a constant fight against this entity, endometriosis. But perhaps not surprisingly, this transformation to the new body was not always seen as something negative but could have positive qualities. Despite reductions in bodily functioning, the diseased body can sometimes facilitate women's access to the elusive reward of the endometriosis label.

II. Women Talking About Their Diseased Bodies

Women rarely spoke directly about what Mol (2002) called the physicalities of their chronic disease. They focused more on the effects their condition had on impairing their ability to function and to live their lives as they previously did. It was only through images that women expressed their physical pain. Endometriosis was enacted through visual representations linked to violence, monsters usually from within (the 'monsters within us', the 'uterus monster') and imagery of knives and blood. Such notions expressed physical and emotional pain. However, the women still borrowed from biomedicine as they erected their own new forms of 'pain scales', similar to the way of 'measuring' pain in a biomedical setting.

In my fieldwork online, I recognized that patients were using visual representations of their feelings and experiences as a way of concretising what they wanted to say about endometriosis and their bodies. Visual representations of physical symptoms were widespread. Patients often posted images relating to menstrual bleeding or their experiences of pain. It is in this visual medium that they articulated pain, fear, and grief that they were generally unable to verbalise, a finding consistent with Morris's discussion (1998) of visual expressions of pain and the difficulty in finding words to express pain symptoms.

Pain in and of itself was rarely discussed except in relation to a specific question about current pain levels. This discussion took on a rather biomedical tone with patients often asking '*do you mean as in from 1 to 10, 10 being the worst pain?'*-SSI. In addition patients often went on to describe this pain using biomedical terms such as '*stabbing pain*' or '*throbbing pain*' -SSI. While this can also be said of the online support groups I studied, it is on the website relating to endometriosis and art that pain was more clearly represented. I have found that patient expressions of pain are far richer when portrayed on online images than in other forms of expression.

A. Imaging of Pain

Below are several images, presented by women with endometriosis, that express pain in different forms.

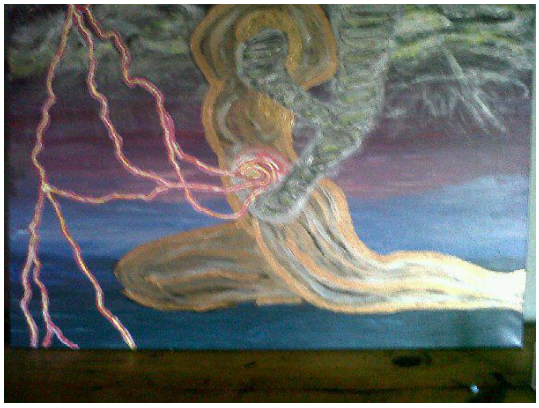


Figure 8.1
An abstract portrayal of endometriosis pain: encircling, piercing and constricting the body.

Figure 8.1 reflects turmoil coming from the pelvic area. There are two types of negative energies arising in the lower abdomen. The first is a red line signifying power or lightning coming from the pelvic area. The second negative energy is represented by a dark cloud linking both the pelvic area and the head/mind of the person. The individual's face is hidden, obscured by the powerful force emanating from the pelvic area. The pelvic area seems to be the most important feature, the part that is in control of the rest of the body.

Figure 8.2
Watercolour entitled "Comfort": illustrating the false comfort of coping with the pain by kneading the abdomen.

This piece of art in watercolour (Figure 8.2) shows a woman's bust. Her fingers, painted in white contrast with the rest of the work which is in colour. They appear to be clawing at whatever is inside the abdomen. While this work is named 'Comfort', one commentator notes that it '*looks more like discomfort*'-O. It seems to portray abdominal pain; the poster and critics agree that it reflects their own day-to-day lives with endometriosis. One even states '*I strike this pose almost everyday!!!!*'-O.

Figure 8.3
Characterizing of the pain as stabbing lighting bolts causing the individual to scream.

Figure 8.3 depicts a person in pain saying '*ow*'. The individual is bent over holding her arms in front of her abdomen. Red lightning bolts are coming from the figure's abdomen. It seems that the pain is represented as lightning, perhaps representing a form of shooting pain. The poster says '*Sure most of you can relate to this one.....*'-O. One woman wrote that she was '*going through it right now*'-O. Another woman commented on this image as follows:

> *I need to share something awesome. I have been having myofascial release done for the past 3 months and I have had the biggest breakthrough in my pain!! I have had 3 periods where I have been able to function!! It's unbelievable how much it has helped me!! NO more narcotics!!!*-O

It seems that her comment was meant to be in contrast to the image above. She was ecstatic, as she no longer experienced the pain the image represents.

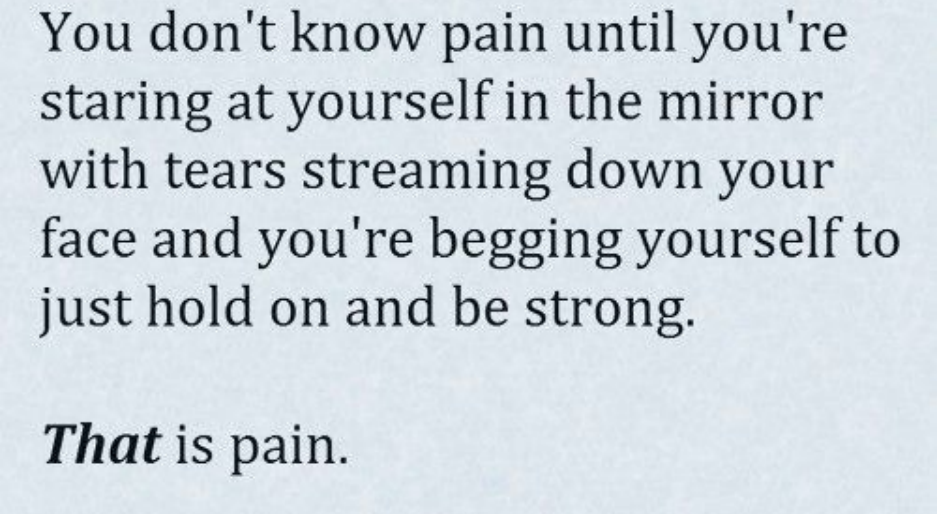


Figure 8.4
Defining pain in the words of the woman with endometriosis.

Women often felt that others did not and could not understand their pain. The text shown in Figure 8.4 reinforces the very idea that you can only 'know' pain if you have yourself experienced it while '*staring at yourself in the mirror with tears streaming down your face*'. Another significant element here is the need to be strong in the face of such extreme pain. '*Beg… yourself … to just hold on and be strong*.' This is the experience that is defined as pain. As it states '***That** is pain*'.

The visual representations of pain in such ways shows an enactment of endometriosis that surpasses the verbal images used in a medical chart to describe the patient's complaints of pain. The visual illustration of pain and discomfort also is more gripping than the surgeon's photograph of endometriosis tissue seen during laparoscopy of the abdominal area.

B. Pain Scales

Women largely disagreed with the biomedical terminology related to pain. While they felt unable to discuss pain without terms such as 'stabbing pain' or 'referred pain', they posted online new ideas of how pain scales, traditionally used in medicine to characterize a patient's pain, should look. Figure 8.5 shows two different pain scales, the top one is generally used by medical professionals. The bottom pain scale

represents a chronically ill person's scale in which all the faces are smiling, despite the different levels of pain. This suggests that a scale linking pain to facial expressions of pain is not useful for chronically ill patients, who learn to hide their pain through the 'mask of health'. Therefore, experiencing different levels of pain will not show outwardly. Much has been written on pain scales and pain expression in chronic pain (Morris 1991, Prkachin 1992, Prkachin et al 1994, Breivik et al 2008), with studies on chronic back pain patients, for example, showing that patients are successful at inhibiting reactions to repetitive pain (Craig et al 1991).

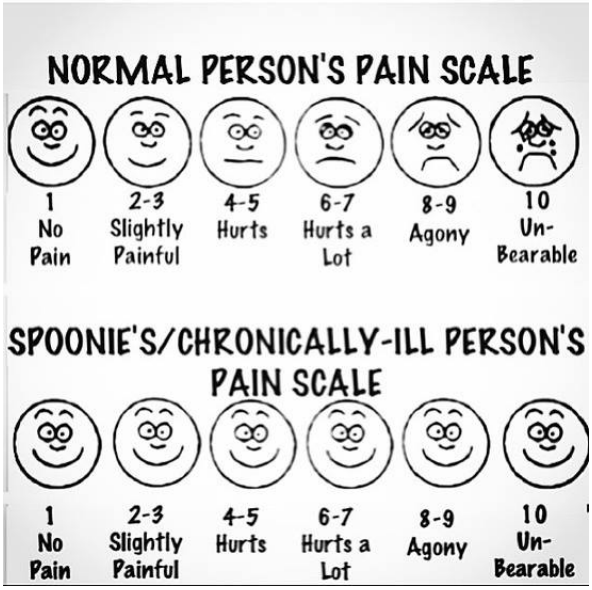


Figure 8.5
Comparison of pain expression in normal and chronically ill persons.

Figure 8.6 also challenges current pain scales. The woman who posted it with hash tag endometriosis titled this an '*endo pain scale*' that was '*too serious for numbers*' suggesting that a few numbers cannot capture the level of pain these women experience.

Figure 8.6
Pain scale posted by a patient with endometriosis: *'endo pain scale … too serious for numbers*'.

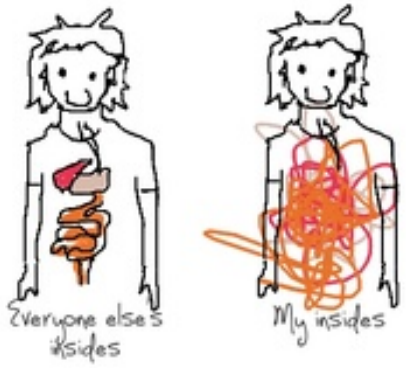
Thus, the patient's enactment of endometriosis pain differs from traditional biomedical characterizations. The endometriosis pain scale should be different from the usual pain scales. Two notions become clear: (1) Endometriosis is so painful that it does not fit within medical notions of pain, its pain is 'too serious for numbers'; and (2) Women with endometriosis do not present (clinically with respect to pain) in the ways usually expected by clinicians. Thus, this enactment of endometriosis is in direct conflict with enactments of endometriosis within clinical settings.

C. The Monsters Inside Us

Women with endometriosis often posted images of what they imagined their insides looked like. Figure 8.7, below, posted on a site for young women with endometriosis, shows a comparison of a 'normal' body and a young woman's endometriosed body. 'Everyone else's insides' shows a drawing of an uncomplicated gastrointestinal tract, whereas her sick 'insides' are depicted as a multi-coloured disordered scribble. This suggests that the organs typically found in the body are chaotically organized. The stomach, intestines, and liver clearly depicted in the image on the left are no longer clearly delineated in the image on the right.

Lacey, who posted Figure 8.7, expresses feelings of internal chaos that suggests the presence of adhesions (internal scar tissue), and endometriosis implants inside her. The

contrast between her 'insides' and 'everyone else's insides' is striking and implies that she views her body as structurally flawed.



'endogirls pinterest' Figure 8.7
A drawing posted by a young woman with endometriosis showing the internal chaos in her insides as compared to the organised structure in everyone else's body.

Figure 8.8
Image of knotted up yarn and strings posted by a woman to illustrate adhesions in her own body.

Simea, who posted Figure 8.8, wrote '*this makes me think of adhesions or endometriosis. Interesting visual'*-O. For her, an image of knotted up yarn and string represents what is happening in her own body. Such visual images (Figures 8.7 and 8.8) move away from the biomedical and employ notions of chaos or messy disorganization that replaces anatomic clarity.

Women also spoke of monsters they felt were now inside them. While this was metaphorical, these monsters were depicted either more generally, or through association with gynaecological organs such as the uterus, the ovaries, or the endometrium (the lining of the uterus). Women posted many images online, describing what they called the '*uterus monster*'. This monster was depicted in several different ways, as we will see below. Interestingly though, by naming it the '*uterus monster*', one sees a distancing of the uterus. It is placed clearly as something external to the self, but perhaps still part of the body, so much so that it is seen as something with monster qualities. It is unclear whether this can be considered the sort of fragmentation of self that Emily Martin (1987) described in her research participants. For Martin, women when speaking of menstruation would split the body from the self, feeling that their body was doing something apart from the 'self'. I have considered this, but while the women here do speak separately of the 'uterus monster' or the 'attack of the endometrium' for example, it is not clear they see their bodies as separate from their 'selves'. Instead, it may be more of a shift from the original body to the now 'endometriosed' body, the sickened or diseased body. The shift from old to the new, from one body to another, but not a separation of self and body – at least separated was not how they expressed it.

Jessica posted Figure 8.9, a piece entitled 'Uterus Monster' from the Gross Anatomy series by Kipling West. She said '*I don't know, it seems a bit too friendly, more alien than monster...I imagine an #endometriosis uterus monster to be more threatening and gruesome!'* She then asks *'How do you picture your endo-monster?'*-O.

In response, Susan said '*I picture mine like a fiery porcupine with edward scissor hands*'-O. These two women felt that they in fact had a uterus monster. It is theirs, it is in their bodies. It is far from friendly and a true monster, with perhaps scissors and fire.

Figure 8.9
The Uterus Monster.

Figure 8.10 suggests that the uterus is there to create havoc and to cause pain. This idea is depicted in a cartoon in which the uterus introduces itself and says, '*Hi, I'm a uterus. I'm here to ruin your life.*' After several episodes of causing worsening pain, it announces that '*I'm Done*', only to turn around and say, '*Just Kidding!*' Then, its true self comes out, and you see the teeth that one might associate with the 'Uterus Monster'. Janet posted Figure 8.10; she stated ''*Oh hai. Story of my life*'-O.

Figure 8.10
Panel of cartoons showing the uterus depicted as an independent individual tasked with disrupting and poisoning the entire body.

Women often also posted images related to an ovary that is attacking the body. These images regularly featured knives. Figure 8.11 shows a woman smiling and saying to a man in Spanish, '*Therefore something like this is ovarian pain*'. Here, there appears to be many monsters carrying knives and even a chainsaw. The violence is evident,even though the woman appears to be sharing a joke with someone.

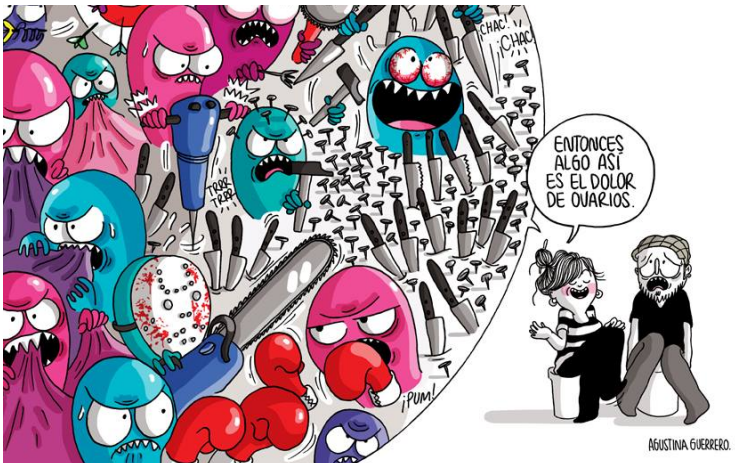


Figure 8.11
A description of pain in Spanish with monsters carrying knives and a chainsaw.

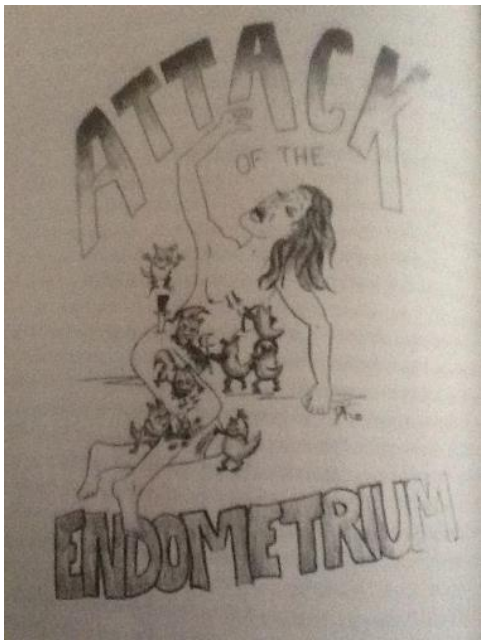


Figure 8.12
A depiction of the attack of the endometrium, with monsters attacking the body.

All of the gynaecological organs become something fearful, terrifying, and capable of unleashing an attack. Figure 8.12 shows the 'attack of the endometrium' in which little monsters with knives are attacking the whole body except for the face and her feet. Judith, in posting Figure 8.12, said simply **'***This is Us Ladies….*'-O. For her, this image represents endometriosis. The notion of being attacked by one's own internal organs is again suggested by a fairly common online phrase seen in Figure 8.13:

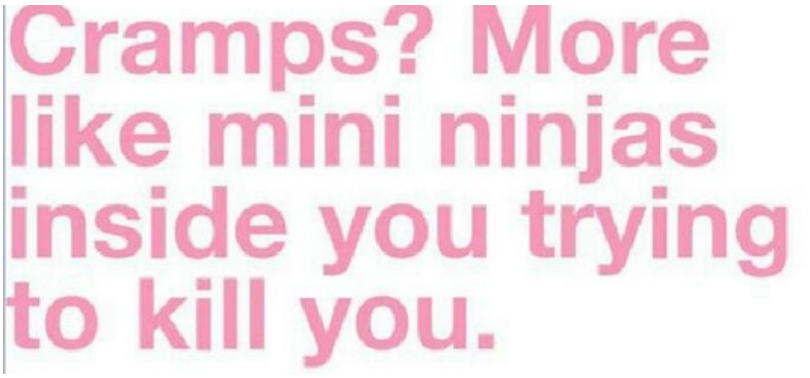


Figure 8.13
A post describing the common notion of being attacked from the inside.

Jane, the woman who posted Figure 8.13 said: '*Oh so very true*'-O, while Haley responded by saying *'I call my cramps "clamps" heck even labor pain after my water broke, was only mild discomfort to me vs. when my uterus has clamped up in pain!'*-O. Catherine agreed with her: *'Yeah endo cramps are worse than labor. With labor you have breaks between contractions at least'*-O.

Despite viewing their gynaecological organs as monsters, or beings that attack from inside, women also posted about internal monsters relating to fear and grief. 'The monsters inside us' then take on another quality, not just those monsters that cause physical pain but those that cause emotional reactions such as fear and grief.

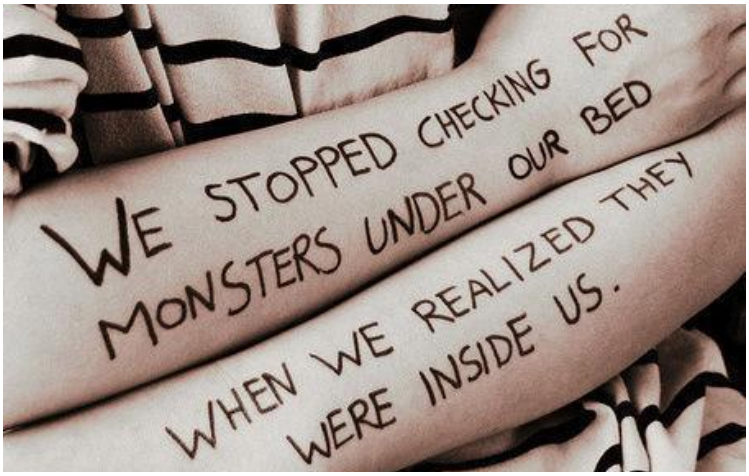


Figure 8.14
The monsters are inside us.

Figure 8.14 says, '*we stopped checking for monsters under our bed when we realized they were inside us*,' # endometriosis. This implies transformation of external fear into an internal force. While originally seen as pain external to the body, it eventually becomes an internally embodied element. In response to Figure 8.15, Ally commented, '*Heartwrenching, especially when young girls suffer from this agonizing pain'*-O. Ester noted: '*I really like this one! Not just for endo pain but for all kinds of lessons to learn in life'*-O. Olivia said that: '*It is good for all invisible illnesses*'-O. And Janet felt that Figure 8.14 '*reminds us that despite our internal struggles we are stronger than we realize'*-O.

Figure 8.15
Image identifying parts of life with endometriosis: pain, monsters and loneliness.

Lucy who posted Figure 8.15 said

> *This piece keeps popping up in my searches. #endometriosis I haven't posted it until now for a reason I am not sure of but today it feels right. I can identify parts of a life with endometriosis in the picture today. Heartbreak, pain, monsters no one else sees, loneliness, feminine curves, bleeding etc.* -O

For Lucy, this image represented much more than physical pain. She saw heartbreak, loneliness, and monsters no one else saw. The monsters represented the hidden pain and the isolation. (See Chapter 7 for a discussion on endometriosis and isolation). Joslyn echoed this sentiment. She saw '*[s]cars, tangled hair, [and] keeping the pain in'*-O.

I note here that the 'uterus monster' does have strong parallels with the notion of the 'wandering uterus' that I discussed in Chapter 3 with its mobility, its unruliness and its capacity to harm and to attack different organs .

D. The Body Betrays Me

Figure 8.16, posted online with #endo, shows a woman with her shirt pulled up to display her abdomen with '*Out of order*' written on it. The message is that her body is somehow not functioning properly. Instead of being a 'normal,' healthy body, it is flawed and has failed. June comments that '*I feel like mine should say "under construction!*"'-O, while Sue notes '*I know the feeling.*'-O And Jill suggests that this will be her experience until her next surgery:

> *Me till my surgery in May. Every move and I feel the tearing. I come back stage 1 every year, didn't go into remission in pregnancy, am not allowed to have more children.*-O

Figure 8.16
The abdominal area and its organ strike a pose of a localized landscape which is out of order and affects the functioning of the overall body.

Figure 8.17, a work entitled 'Endometriosis', states '*my body slowly betrays me*'. I see a woman slouched over the frame that holds her up, while the internal flames originating from the womb take over her entire body. In posting Figure 8.17, Jane said '*Endometriosis pain is something you never get used to*'-O while Will, a male, writes '*Ouch, pic captures the torment I am happy not to experience*'-O.

Figure 8.17
A work titled 'Endometriosis' by Masonic Boom/Karen D. Tregaskin suggesting the sensation of burning spreading from the uterine area through the body.

E. There Are Now Limits

Many images posted by women also betrayed a feeling that '*there are now limits*' to what they are able to do. Some posted images gave a message of semi-acceptance of the new body, where they acknowledged pain, or other symptoms of endometriosis while also explaining that it was something women had become accustomed to. Figure 8.18 explains '*It hurts, but it's ok I'm used to it*'. The words imply there is an adaptation to the 'new normal', albeit one that remains uncomfortable.

Figure 8.18
Words alluding to the adaptation to the experience of pain with the setting of a new state of equilibrium.

This new normal has different limits and is associated with certain emotions that can be difficult to deal with. Figure 8.19 explains that '*dealing with the pain is actually the easy part. The hardest part is dealing with all the emotions and understanding I now have limits*'.

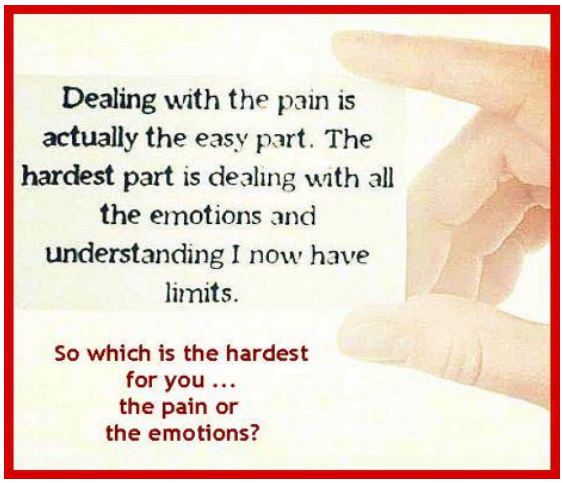


Figure 8.19
An illustration of the phases of confronting pain and then the emotional adaptation.

Figure 8.20 explains the 'new normal' a bit further by placing the 'new body' in contrast to 'normal'. It states '*How do you answer the question, "how do you feel?" when you've forgotten what "normal" feels like?*' The woman who posted this simply stated '*sadly*', implying that she had the same experience.

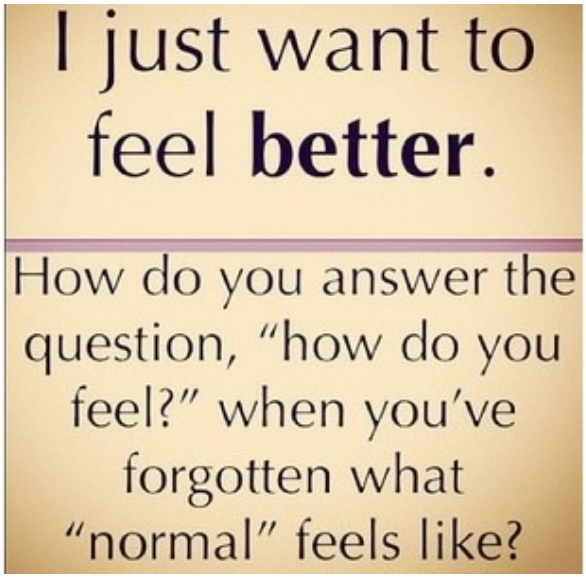


Figure 8.20
A reflection on the wish to return to pre-pain status.

III. The Failed Body

I have discussed in Chapter 7 how the new endometriosis label affected women, who described their inability to fulfil their roles as a sexual partner and mother. Here I focus on other presentations of the failed body. I begin by considering how women have difficulty fulfilling simple tasks in their daily lives. I then move on to look at how endometriosis forces a change in life plans and I examine the ways in which it affects women's relationships.

A. Spoon Theory

Online women spoke a lot about 'Spoon theory,' an idea that is applied generally to people with chronic illnesses like endometriosis. 'Spoon theory' has to do with the notion that the chronically ill may have only limited 'energy' to use throughout the day.

While a 'normal' person may have extra spoons (or energy) at the end of the day, a person with a chronic illness usually has none left. Spoons (symbolising activity or energy units) are used for daily activities such as brushing hair, brushing teeth, going to work, picking up the baby from the floor, and walking up stairs at home. Women are left to find ways of limiting their activities and have to choose among different daily activities. Judith explained that

> *Actually what I can't do is constantly be on the go doing housework all day but nobody offers to do ironing or your hoovering or any of those things even after you've had an operation but they think I can't lift a heavy box. They just don't quite get it all really.*-SSI

Rachel noted that before and during her period, she is unable to do anything. She can't concentrate on work, and even while watching television she keeps shifting around trying to find a comfortable position. She is unable to accomplish tasks during this period because of the pain.

> *Before & during a period, I have to stop everything else, can't concentrate on work or e.g. watching TV, just have to keep shifting around to try to get comfortable and wait it out.*-Q

The daily choices that women make about where they might expend their energy highlight how endometriosis brings with it a pressure to accomplish daily tasks despite a body that may not cooperate. The women spoke of guilt when they failed to find the energy to fulfil their usual chores. Seear (2009) reported similar comments in describing her research with women with endometriosis in Australia. Thalia commented that:

> *For many years, I struggled to cope. I kept my job by getting a lectern and spending most of my day standing up. I would come home in a state of exhaustion and rest all evening in a special banana chair, that allows me to recline, before that I used to lay on the floor when I got home from work.*-Q

After work she would need to rest. She described a state of exhaustion that forced her to stay all evening in a reclining chair. Even the expectation of moving and getting out of bed was sometimes too much. Figure 8.21 shows a person lying down with her arms crossed over her pelvic area, with her mouth open. It states '*things I don't feel like doing today: MOVING*'. Something so salient in daily life, '*moving*' becomes a complex and very difficult task.

Figure 8.21
This figure captures the essence of the spoon theory: hopelessness, helplessness, and limited mobility.

Figure 8.22 takes this notion of inability to accomplish simple tasks one step further. The cartoon depicts a woman who wakes up with a positive attitude and many plans for the coming day. However, the cramp and then '*unbelievable pain*' force her back into bed. Despite her earnest desire, she cannot accomplish what she wanted at the start of the day.

Figure 8.22
Cartoon depicting how the motivation to become more active is stunted by cramps.

It is here that the comparison between the new body and old becomes very striking. Something that was so simple before becomes a chore, including sitting. '*My problem is that I've had problems sitting which has limited my social life*'–Q said Tara.

Figure 8.23
Pain renders more complicated the simplest of mundane activities.

Figure 8.23 suggests that doing anything that requires putting on trousers or 'pants' in American English is just too difficult at the moment. Judith, when she posted Figure 8.23, simply stated '*pretty much*'-O. While putting on trousers may seem like a rather simple thing to do, many women found this quite complicated. Women often spoke of having to find creative ways of avoiding pressure caused by wearing tight clothing in the pelvic area. Coping strategies included wearing maternity clothes, yoga pants, always dresses. This was often felt to be yet another part of endometriosis that questioned one's femininity.

Women also spoke of losing the luxury of engaging in extracurricular activities. This represented an inability to take part in activities they truly enjoyed at the expense of the necessities of life such as eating, cooking, and going to work. Malory explained that

she had to give up running. Endometriosis ultimately affected all aspects of the women's lives, from social interactions, to work life, and to sleep.

> *Psychologically I have been very affected by endometriosis; the disease has had an effect on my work life; I have missed social appointments etc. because of it. I always have to make sure I get enough sleep, eat regularly, and don't over-exert myself. I like to keep in shape and enjoy exercising, but keep suffering setbacks. I will go out for a run only to have to stop because I have abdominal cramps. Trying to get in and stay in shape is therefore a constant battle.*-Q

B. Change in Life Plans

Women additionally spoke of having to change their life plans and accept the limitations in their lives. Alicia explained that the expectations for her life had not been fullfilled. She thought that by her present age, she would have been able to own a house and obtain a teaching job. She trained to be a teacher thinking that she would have already been placed in a school. Now, she has had to adapt. She has started her own business as a private tutor.

> *I finally qualified as a teacher, primary school teacher, in 2008 but it took me five years although it was a 4 year course. I took a year out because of my pain being so bad. My exams and course-work all suffered because of the pain I was in. And now I do my own tuition. I run my own business because I find I can be my own boss and if I'm not well then I can take a day off or I can work the tuition very much around how well I'm feeling.*-I

She felt guilty because she was not able to be a '*good adult daughter*'-I. She ought to have moved out already, to be independent. '*Financially they've had to help out because I can't support myself*'-I. She explained that at the moment this was not possible, both financially and in terms of chores and daily activities.

Carrie stated that she had a full-time job before she was diagnosed with endometriosis. Since her illness she had been unable physically to handle the hours. She was lucky to have found a job share. She admitted that her forward momentum in the company had likely been affected. Similarly, Valerie explained that 'the course of my professional life has been dictated to my employer and myself rather than being a series of choices made from entirely free will'. She had to make decisions regarding her career as a

consultant orthopaedic surgeon because of the endometriosis and associated pain levels and fatigue. She explained that:

> *First I gave up any work outside my core NHS role (mid 2011) - so no private practice, no NHS work in the independent sector, no medical reports… no additional income. Then I rearranged my timetable so I only operated in the mornings (Nov 2011) as my pain level and fatigue by the afternoons led me to feel I was not reliably safe to be operating. Then I came off the on call rota (July 2012), long before my "turn" since there were other (older) consultants in the dept appointed long before me who would have been keen to stop on calls and "by rights" should have had that opportunity before me. That allowed me to change my work pattern further and have Wednesday as my day off so I had a mid week break [still full time over 4 days] I have been supported by my department and NHS trust - management, consultant colleagues and occupational health have all been understanding and accommodating. That doesn't stop me feeling that the course of my professional life has been dictated to my employer and myself rather than being a series of choices made from entirely free will!*-Q

C. Interaction with Others

Women spoke of the difficulty in explaining their inability to fulfil expectations of others. When asked how endometriosis had affected their lives, all suggested that endometriosis affects relationships. The one place where women discussed feeling understood and did not feel that they had to put on a 'mask of health' (see chapter 7) was in the various support groups. In the groups, they felt comfortable, as if someone could understand their experience. Taking down the mask of health often contributed to increased struggles within relationships. In admitting to the inability to do something, cracks began to show in interpersonal interactions. The women spoke of feeling that they had let others down.

1. Families

Most women suggested that to a large extent their families did not entirely understand their problem. They explained that because of stigma, endometriosis was generally a difficult topic to speak about. This seemed to contribute to family members' not understanding how endometriosis affected the women. Still, many women continued to interact with their families despite having relationships that were strained. Valerie

found it difficult to speak to her father about endometriosis. He did not appreciate the extent to which endometriosis had taken over her life. '*He seems to have a very limited understanding of my experience of the disease and how time-consuming and all-encompassing it is for me'*-Q.

Valerie talked about how the relationship between her and her parents-in-law was affected by their inability to understand her. Their '*pitying'* her resulted in a strained relationship between Valerie and her parents-in-law, and also between her husband and his parents.

> *Relationships in my family haven't really changed very much but things have been a challenge with my parents in law - not really understanding but pitying me for the aspects they do understand and not "getting it" overall; causing my husband to become angry with them. Then barriers develop[ed] because of those issues and because we have found it difficult to socialise with them as often as they would like due to my health problems.*-Q

Kristin stated that she was unable to attend fully her sister's wedding. To this day their relationship has suffered. Similarly, Catherine spoke of a change in her relationship with her daughter. As an example, she explained that her condition prevented her from attending a car boot sale with her daughter. *'I don't think she has ever really forgiven me. She still mentions it'*-SSI. Susan has had many arguments with her husband because of endometriosis. She explained that her condition

> *has caused many arguments with my husband over the years. Frustration that I cannot always have sex and also feeling of helplessness when he cannot help me.*-Q

Figure 8.24 shows a cartoon in which a doctor is speaking to the wife of a patient and explains that '*The uterus transplant was a success. I'm sure you'll find your husband much more understanding now.*' The implication is that her husband previously showed little understanding about her experience of endometriosis. Now that the husband has the wife's uterus, he will be more empathic.

Figure 8.24
This caricature represents the husband who received the transplanted uterus and will hopefully be more compassionate.

While much of the narrative linked to relationships with family was on the lack of understanding, some women also spoke of feeling that endometriosis has caused sadness amongst their family members. Valerie explained:

> *I don´t need to explain how not being able to have children affects not just you, but other family members as well. I am only child and my mum longed for a grandchild but she died prematurely at the age of 63, without experiencing that joy and I think it was a great sadness to her. Knowing this often makes me very sad too.*-Q

While most women spoke of a deterioration in their relationships with family members resulting from a lack of understanding and sadness, some also suggested that family bonds were strengthened by the collective struggle with endometriosis. Judith explained that because of endometriosis '*[m]y husband and our marriage have been put under considerable strain'*. She wished she had understood '*how much more I needed to nurture my husband, because endo isn't just my problem'*. But from it she has learnt to acknowledge that endometriosis is not just her problem but also affects him.

Valerie also spoke of how endometriosis affected her marital relations. She explained:

> *The infertility has put a severe stress on my relationship with my husband, because it has made me angry, sad, irritable etc. As has the endometriosis pain. He has now learned to sometimes ask me: "Are you in pain now"? when I am*

> *being short with him or irritated. But our bond has always been strong, and has probably been strengthened by this ordeal.*-Q

In her case, while the marital stress was caused by endometriosis, the condition may have strengthened their bond by forcing them to join together in confronting the difficulties.

2. Friendships

In contrast, if friendships were markedly affected, these relationships did not last. Instead, women explained that their friendship groups changed during the course of the illness. Most women spoke of losing friends, and some felt that they did not currently have any. '*To be honest I don't have any friends'*-I explained Allie. However, many said that most of their pre-existing friendships were lost before getting ill and that this change in friendships could be a positive experience:

> *It has curtailed my social life - many cancelled arrangements, money wasted on concert/theatre tickets, feelings of isolation. Probably lost some friends… but discovered who in my life is worth their weight in gold!*-Q

It became clearer who could be considered true friends. In a sense, those original friends were re-classified as non-friends or at least less close friends. *'I have probably lost some friends but my close friend relationships have strengthened as I know who has been there for me and I value that enormously'*-Q. While many women spoke of the quality of friendships and learning to distinguish good friends from others, some women felt that endometriosis affected their friendships because it dominated the conversation.

> *Endometriosis has affected my relationship with my friends in terms of me discussing my symptoms with them and them sometimes trying to give me advice. At times when my symptoms have been bad and I had not had any answers from the doctors, the discussion has been pretty much taken over by my endometriosis and of course I am not happy with this. I am blessed with wonderful friends, but I often just want to focus on more fun and frivolous things, rather than all that health talk. So in this sense endo has affected my relationship with my friends.*-Q

For Valerie, her interaction with friends had changed from light-hearted exchanges to more serious '*health talk*'-Q. She wished that she could '*focus on more fun and frivolous things*'-Q instead.

3. Workplace/Professional Relationships

While some women found it difficult to explain to others in professional settings how much endometriosis affected their daily lives, most women gave examples of institutions' not accepting that they were ill and unable to accomplish tasks that had been set. It was not uncommon to hear of taking time off and needing 'mitigating circumstances' forms from university, or needing to go through a meeting to get special compensation at a job. Susan explained that:

> *I missed lots of school and college and have had a lot of time off work. People I work with have no understanding of the amount of pain I experience. I have a hot wheatie bag most days at work to help get me through because the pain relief I have to take makes me so sleepy.*-Q

Susan also reported missing a lot of school, college, and work due to endometriosis. She thought that her co-workers had 'no understanding' of the pain she experienced. Janice spoke of her experience at university with endometriosis.

> *Throughout university I had to fill in mitigating circumstances forms a lot. I didn't always use them cause luckily I was doing well but I needed to go through that procedure constantly because of my endometriosis. ... I did well but it was constantly this battle of getting your time so that when you were well you could tell them look I'm not well please understand I'm not swinging the lead and I will make you up. And I always did, but it made you feel guilty constantly. It was awful.*-Q

It was a constant battle to convince her professors that she was truly ill and not trying to get out of doing work. Many women explained that they were reluctant to explain about endometriosis in detail in professional situations for fear of being fired or not given more responsibilities. Bernice stated that:

> *I'm a year to year contract so initially I needed to feel I proved myself at work before I then kind of was really honest. As much as they knew I had it [endometriosis] I don't think I really went into it.*-SSI

She went on to explain she did not want them to '*feel like it interferes and that I can't do my job'*-SSI. For her, if her co-workers knew too much about her endometriosis she risked losing her job.

However, even women who did try to explain about their endometriosis did so in situations in which they were forced to, such as meetings when they justified their absences from work. Most women felt forced to quit, as they did not feel understood or taken seriously by their co-workers. Christy, for example, stated that at her work-place she constantly had to write letters and fill in paperwork to justify her time off. '*So there was all the battle with paperwork and constantly writing letters and constantly having to ask for extra help or extra time and stuff like that'*-SSI. She believed that this had such a profound effect on her that she ultimately left work.

IV. The Emotional Burden of the Failed Body

The emotional burden of the new 'failed' body was very heavy. Women spoke of being overwhelmed, of feeling down, of losing self-esteem, and grieving. These emotions were often linked to the limitations that they felt the new body imposed on them. When these enactments of endometriosis (physical pain, infertility or pain during sex) occurred singularly and predominated, they differed from a more readily diagnosable presentation of the disease. This distinction occurs, too, when a dominant symptom is a mental health manifestation such as depression. The problem is that when this occurs, the patient may find herself in the a-diagnostic category and access to care for the possible underlying condition of endometriosis may be blocked.

A. Overwhelmed

Women believed that endometriosis had taken over everything. This contributed to being overwhelmed by their current situation. Figure 8.25 shows a woman sitting facing a sea of red and pink. Alice, the woman who both painted and posted this explained:

This is a water colour i made when i was considering my identity and self, and the feelings of being overwhelmed by disease.' 'When all i can see around me, ahead of me, surrounded, stranded, is the presence of Crimson. My within is everywhere.-O

Figure 8.25
Watercolour showing the woman's vision of life as bounded by the symbolic colour of blood.

The endometriosis, symbolized by the colour crimson, overwhelms her. The crimson is powerfully ubiquitous and inescapable. She is isolated, cut off, and unable to find a way out. This led to a feeling that some days became stifling and difficult to penetrate.

Figure 8.26 shows a woman lying on a couch in the fetal position with her arms and hands covering her face, suggesting that she is crying. 'Some days, I break' it tells us. The woman who posted this stated 'more days than I would like.'

Figure 8.26
Picture illustrating the feeling of being overwhelmed: in a foetal position and face covered to avoid the external world.

Janice explained that

> *I think you get quite obsessed it takes over I like at times to forget I've got it and try and just function cause I think if you get too into it … it can take over a bit and get you in quite low mood.*-SSI

For her, endometriosis can become a fixation, something there all the time that feels overwhelming and that ultimately lowers her mood.

B. Feeling Sad

Women spoke of feeling down when directly asked about it, though they rarely volunteered such information. They were surprisingly open about their mood changes, given the potential for stigma. Few women stated that they rarely if ever felt down. Those few who reported no changes in mood also reported few symptoms of endometriosis. Those who described days in which they felt down were able to link exacerbation of their endometriosis to increased feelings of sadness. Moradi et al (2014) found, through focus groups, that women with endometriosis reported feeling depressed and upset because of the condition. Roomaney and Kagee (2016) also stated that women with endometriosis reported experiencing sadness. In addition, while I did not specifically ask about clinical depression or suicidal ideation, depression is a known co-morbidity of endometriosis (Bitzer 2011, de P. Sepulcri and do Amaral 2009). I did not explore the meanings women attributed to the notions of feeling down or sadness, but do acknowledge the importance of doing so and the abundance of literature debating

the origins and understandings of emotions and sadness (Keltner and Haidt 1999, Kleinman 1980, Lutz and White 1986, Scheer 2012).

Wendy explained that pain can get you down, and that having a period can feel like an illness, forcing her to stay at home. *'The worst pain gets you down! And heavy periods can feel like an illness, and tie you to the house'*-Q. For Ruth, endometriosis affected all of her life. Feeling down was connected to the daily effect that endometriosis had on her life. The constant reminders of endometriosis in the form of tablets, adapted clothing, and heating pads ('wheatie bag') meant she never had a break from the disease. She consistently wondered how endometriosis would affect her. Its ubiquitous presence meant she often felt down.

> *You often get down. It [endometriosis] affects every aspect of your life. You just have to pick yourself up and get on with it when you can. It is a pain to have to think 'have i got all my tablets and my wheatie bag before i leave the house. Am i wearing something loose enough for if my tummy swells.' i dont go a day without thinking about how is it going to affect me today. Swollen tummy, pain on going to the toilet both ways, tired and no energy, bad pain etc. Mood swings too!*-Q

However, Ruth also mentioned 'mood swings' as a symptom of endometriosis. It may be that part of her feeling down was linked directly to the disease itself. Wendy also suggested that hormones might play a part in her feeling down.

> *Otherwise hormones definitely play a part – I feel my cycle of hormones is quite extreme, making me overly emotional, and more so as I get into my late 30s. But I only have one ovary now, too, so it may not be endo that's the main factor.'*-Q

This effect of hormones on mood was felt generally to be a part of endometriosis but was also thought to be the results of side-effects from hormone therapy.

C. Losing Self-Esteem

Women often spoke of losing their self-esteem, and the loss appeared to be connected to the changes women experienced. Being unable to accomplish certain tasks meant that women often spoke of no longer feeling 'independent' or 'strong'. Martina, for example, explained that:

> *I stopped feeling like a capable, independent and strong woman - my self image and self esteem took a considerable hit due to endometriosis*.-Q

Similarly, Bernice pointed out that endometriosis '*knocked my confidence a bit'*-Q. She felt that she needed to prove herself more than before the diagnosis was established. She continued '*I don't want to kind of get labelled that I can't manage so in some ways'*-Q. The inability to accomplish certain tasks ultimately affected her self-esteem and her confidence.

D. Grief

The women spoke often of being deprived of their ability to fulfil their dreams and to live up to the expectations of others. They spoke of sadness, tears, regrets, and hopelessness. Valerie, for example, told of

> *feelings of helplessness, hopelessness (there is no cure) and sadness due to the loss of quality of life, having to cut down on work and perhaps not being able to have children. This is a lot for one person to take.*-Q.

The grief was often linked to being unable to fulfil the roles as a woman that she had dreamt of previously.

Figure 8.27 shows an angel, whose face is resting on her left knee, with red wings that appear to disappear slowly, creating the illusion of blood. Lucy, who posted Figure 8.27, said:

> *As insomnia strikes again, I am moved by this intense and evocative painting, "The End of Dreams" by Beata Belanszky-Demko. For me, it immediately captured the toll endo takes on our minds and bodies --multiple surgeries, removal of reproductive organs, raw and searing pain, miscarriages, infertility, and so many tears. Part of me finds the image somewhat grotesque and wants to turn away, part of me is compelled to keep my eyes on this striking figure.*-O

She spoke of the toll that endometriosis takes on both mind and body with '*multiple surgeries, raw searing pain,*' and '*so many tears*'-O. In response to her post, several women posted comments like '*achingly true*,' '*agree*!', or '*This is awesome*'-O.

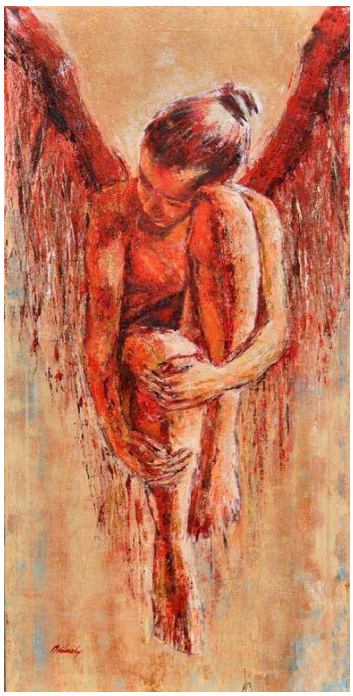


Figure 8.27
'The End of Dreams' by Beata Belanszky-Demko.

Figure 8.28 **Figure 8.29**
Images suggestive of sadness, grief, mourning and loss.

Figure 8.28 suggests a woman curled up in a ball crying, covering her face and appearing as though she has given up. She is not able to face the world. This image was posted as representative of endometriosis. While the woman may be in physical pain, it is clear that this may also represent a state of sadness and withdrawal. Figure

8.29 also evokes sadness and grief. I see a woman dressed in black, looking sad, with mascara running down her face as though she has been crying.

V. Moving Forward in the Failed Body

In this section, I examine how women move forward in their new and changed body. They often spoke of the new body as linked to a constant fight. Others described how they have changed. While this change could be seen as something negative, it was often treated as giving women a new positive attribute or revealing positive qualities that they already had. For example, Alicia explained that her personality and energy had been stolen. '*It's [endometriosis] changed my personality. I feel like it's robbed me of personality and I feel like I've been drained of all energy and personality now'*-I. And Catherine felt that her personality had also changed, but in a way that made her stronger: '*It's made me harder. I feel a lot tougher'*-I.

A. A Constant Fight

Endometriosis symbolizes in some sense a perpetual struggle. The disease is limiting, constricting, and never ending. Figure 8.30, posted by Mary, shows red ribbons encircling an invisible body, with the hashtags endometriosis, painting, and momentum.

> *I think it grabbed my eye because there are times when life seems so constricted, restrained by the impacts endometriosis has on life that it feels like it is slowly entwining itself around you and stopping you from being able to move, to get out of the dark places it has dragged you in to. It is a constant fight to keep moving forward in life.*-Q

Mary described endometriosis as *'slowly entwining itself around you and stopping you from being able to move'*-O forward. It kept her in a negative, dark place. The result was that she found herself in a perpetual battle to move forward. This notion that endometriosis keeps you from moving forward was echoed by Valerie who felt that *'this disease keeps on throwing me curveballs, so I am always waiting for the next symptom or complication to crop up'*-Q. She and others did not feel in control of their endometriosis. She explained:

[I do] not [feel] in control at all, I am just lucky that I am no longer getting the extreme pain I had before my operations. However, the lack of sleep I am now in more control of, and as a result the symptoms I was getting from it like headaches, mouth ulcers, joint pain etc.-Q

Even those women who did feel in control of their endometriosis explained that they kept waiting for the time it would get worse again. If they had a bad day, they began to wonder if their endometriosis had gotten worse again. Rachel explained that I am

Pretty well in control these days, as I feel I've addressed a lot of it through nutrition and self-care, but on a bad day I worry that "things have got worse again" and it's out of control.-Q

Figure 8.30
This figure concretizes the patient's experience of endometriosis as a disease that controls, limits, and progressively suffocates the body's potential for active movement.

Susan explained that whether she feels in control:

Depends on the day and my emotions. I do get good days but i am always in pain. I know I have to have the op and that is out of my control. My womb is

> *twice the normal size and they think it is full of endometriosis. I am trying to wait as long as possible before i have the op. More surgery scares me. I had my last lot of surgery just over a year ago and it took 5 weeks to recover enough to go back to work on reduced hours and a further two weeks before I went back to my normal hours. You never get used to surgery! I cope and deal the best way I can. Life has to go on. Some days are just a lot harder than others.*-Q

For her, the possibility of having another operation is out of her control. She copes the best way she can because life must go on. '*Some days are just a lot harder than others*'-Q.

B. Positive Dimensions of the Failed Body

This transformation was sometimes seen as having some positive characteristics in which women felt that they had gained something from their experience of endometriosis. This group pointed out that despite the difficulties linked to endometriosis, they would not go back to their old selves. Alicia, for example, said *'I wouldn't change it though in many ways – because having an illness has made me more aware of a lot of things I never thought I'd have to deal with'*-SSI. She admitted that she had learnt much from endometriosis. Her awareness of others' troubles made her more understanding. So despite the difficulties associated with endometriosis she believed her experience had some beneficial dimensions. Similarly, Catherine explained that *'It's made me a lot more empathic to people who have illnesses'*-SSI. This is echoed by text originally posted on an endometriosis Pinterest page, which stated '*Often it's the deepest pain which empowers you to grow into your highest self*'-O. Despite enormous physical and emotional suffering, the women here felt that this has allowed them to become better.

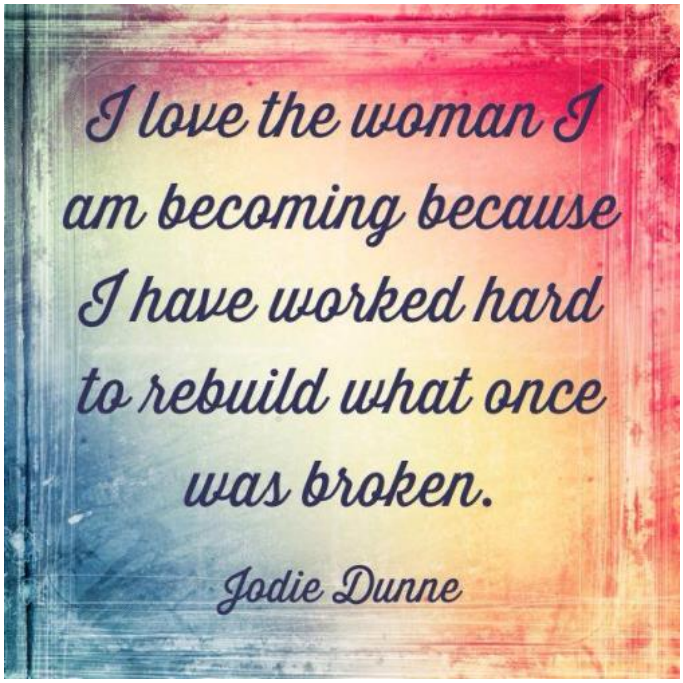


Figure 8.31
Jodie Dunne bearing witness to the positive aspects of the new habitus.

Figure 8.31 tells us 'I love the woman I am becoming because I have worked hard to rebuild what was broken.' While this implies the change is still ongoing, it also clarifies the positive aspects of the negative transformation. Kelly adds:

> *Two days left in 2013. It can be so easy to focus on the negative and bypass acknowledging our achievements. Think back over the year what was one small achievement you should be proud of yourself for? One that no one else necessarily knows about because it wasn't anything big and flashy? Mine was starting to run and walk outside again, away from a bathroom. After all my bowel surgeries and complications I was too scared to go far but now I'm fine. It was a frustrating time and a hard fear to get past but I did and now I'm starting to get back into training again. It will be awhile before I'm doing Triathlons of any distance again but it is a small victory that I am proud of from this year.*-O

She acknowledged the small achievement of the past year. The new limits associated with her new body meant that overcoming something that used to be easy to accomplish should now be celebrated.

Women also spoke of gaining strength from their new body, from their experience of endometriosis. Figure 8.32 shows a bird made of fire, likely a phoenix, a mythical

creature recently made famous through the Harry Potter books and films, which burns up and dies only to be reborn again and again.

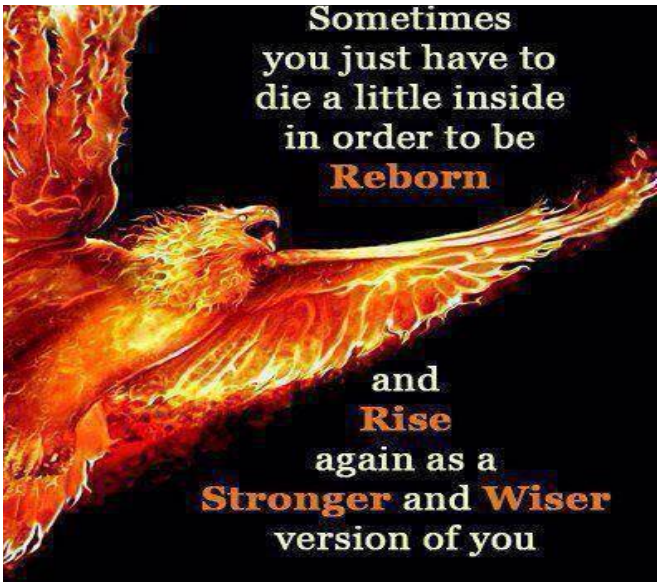


Figure 8.32
An affirmation of the strength gained from the experience of endometriosis.

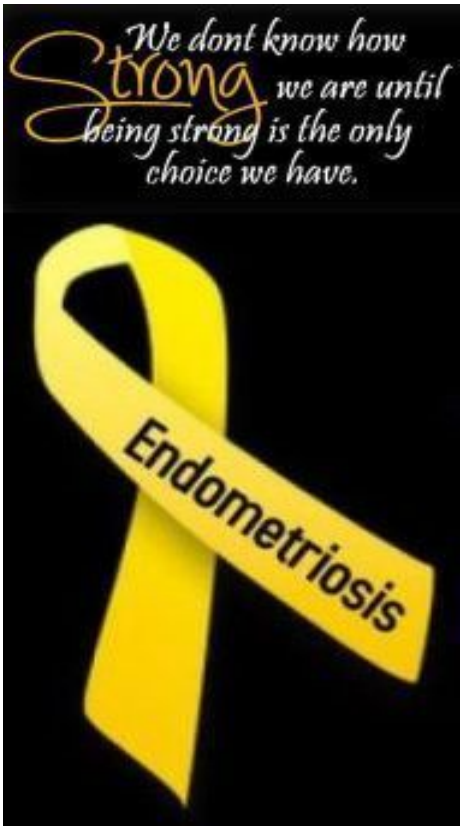
The text explains that '*Sometimes you just have to die a little inside in order to be **Reborn** and **Rise** again as a **Stronger** and **Wiser** version of you*'. Jamie who posted Figure 8.32 noted that:

> *There are days when life with endo feels like the first part. There are ALSO days when life with #endometriosis feels like the second part. I like to focus on that second lot [o]f days.*-O

For Jamie, endometriosis may have caused her to die a little, but it also allowed her to be 'reborn' into someone who learned from the suffering and became more resilient and functional.

While some women spoke of their new strength, others explained that they had learnt how strong they really were. They suggested that they always had some internal fortitude. The suffering brought on by the disease put them in touch with a core they had not acknowledged before. It allowed a woman to explore and acknowledge her own

strength. Figure 8.33 explains that 'We don't know how strong we are until being strong is the only choice we have.'



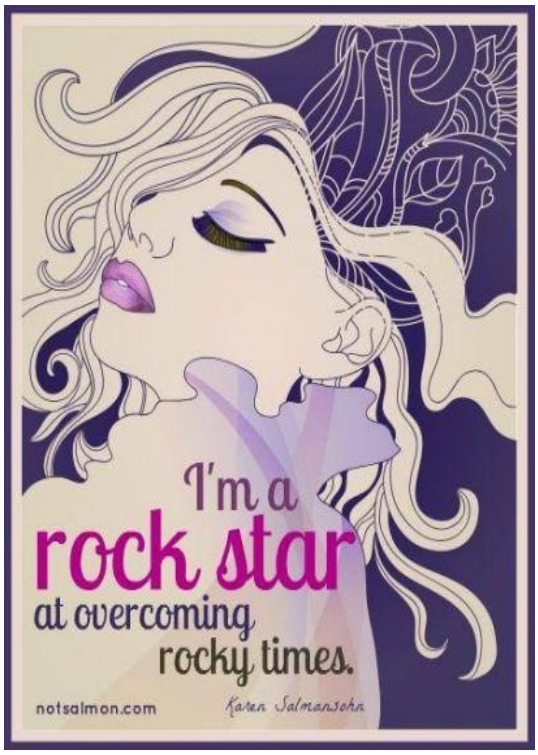


Figure 8.33 **Figure 8.34**

Figure 8.33: Poster acknowledging internal fortitude brought to light by the disease.
Figure 8.34: Poster illustrating the positive vision of women who have overcome difficult times.

Women began to have a different vision of themselves. Statements such as '*We are strong, aren't we?*'-F and '*we just get on with it*'-F were quite common sentiments expressed by the women. Getting through hard times gave women a feeling of strength and of pride. Figure 8.34 shows a glamorous looking woman with pink lipstick who tells us '*I'm a rock star at overcoming rocky times.*' Dealing with hard times took on a positive quality: being able to overcome difficulties evoked pride in the accomplishment.

> Suffering can lead to positive change and to being a 'survivor'. While the term 'survivor' itself was only rarely used, the idea of overcoming difficulty and

emerging as a different and improved person was common. Figure 8.35 shows a woman with wings; it says '*She's strong, she's determined, she's a survivor*'. The woman who posted this explained:

> *Another vibrant mixed media piece by JC Spock, "Survivor Girl" -- loving her prints and how they are so relevant to women facing challenges in their lives, as all of my endo sisters do.*-O

For her, women with endometriosis may all be '*survivors*'-O.

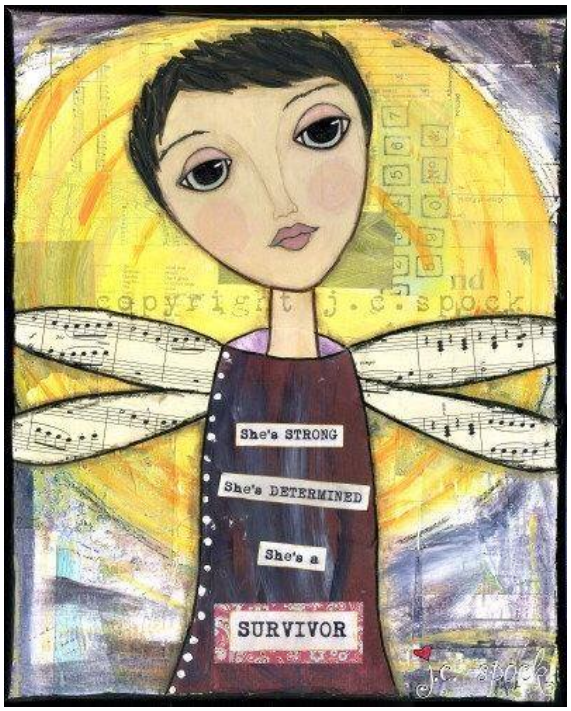


Figure 8.35
Mixed media art by JC Spock entitled 'Survivor Girl'.

VI. Conclusion

In this chapter I have focussed on the phenomenon of patients talking bodies, of women with endometriosis discussing the failed aspects of their diseased bodies. There is a uniqueness about these enactments occurring outside of the biomedical sphere and fashioned by patients with endometriosis. The non-biomedical enactments differ remarkably from biomedical understandings and representations of endometriosis.

Women with endometriosis also recognize multiplicity in their enactments of endometriosis. But what remains consistent for them is the notion of change from the old body to the new. I have looked at visual representations of the now 'failed body' and how the disease limits women's ability to fulfil their previous roles. Women reported how simple tasks such as housework had become difficult, a finding paralleled in Seear's (2009c) work on women with endometriosis in Australia. Women also discussed how this new body affected their interactions with family members, friends, and co-workers as previously discussed by Whelan (Whelan 2009). Women explained that their life goals were disrupted as a result of endometriosis, findings echoed by previous qualitative research on endometriosis (Cox et al 2003a, b and Denny 2004).

The new 'endometriosed' body caused women to experience grief, depressed mood, and low self-esteem (Roomaney and Kagee 2016). Women also stated that endometriosis overwhelmed their lives. My findings thus largely echo previous qualitative work on endometriosis. However, unlike previous studies, women with endometriosis in my study described lessons that they had learned not only in negative ways as previously discussed by Denny (2004) and Seear (2014) for example, but also in positive ways from the suffering caused by this chronic condition. While linked to very difficult experiences, endometriosis could still impart some positive lessons to be learned from those who managed to find ways of coping with the illness. In their own ways, the women suggested that surviving the illness allowed them to take stock of their experiences, to learn something about their inner selves, and to fashion a distinctive form of adaptation to their disease.

While I discussed enactments outside of the biomedical settings, many such enactments place themselves in direct contradiction to medical notions of endometriosis, be it through representations of pain or through the notion that part of endometriosis is the mental health dimension. These enactments of endometriosis therefore may also represent forms of resistance against biomedical notions of disease and of women's bodies not unlike what Martin describes (Martin 1987). So while these enactments are

separate from the clinic, they also impact on the clinic itself, as we saw in earlier chapters.

Women with endometriosis 'talked bodies' in a way that reminds us of Mol (2002:14) and her suggestions that such discussions do tend to emphasize formulations about impaired bodies, about how 'living with an impaired body is done in practice' (Mol 2002:15). The women's talk of their bodies focused more on loss of function and alterations of activities within their daily lives. However, the visual images used to describe their emotions linked to pain, sadness, and other feelings relied surprisingly on their own anatomic rendering and artistry. Thus, the women too 'talked bodies', but in their own unique fashion.

CHAPTER 9

Endometriosis and Advocacy

I. Introduction

In this final chapter, I discuss how the women incorporate their understandings and experiences of endometriosis into the endometriosis movement. While I have largely examined the UK movement, online sources speak to the movement more broadly, and provide information coming out of the USA and Australia, for example. In this chapter, I present the consequential effects of the a-diagnostic category and the multiple enactments of endometriosis that I have discussed throughout this thesis. The endometriosis movement brings these elements together into a single entity.

The endometriosis movement exists also because of a collective affiliation, a biosociality (Rabinow 1996), linked to one label whose definition appears to some extent to be fixed and therefore singular. Here again, I observe a struggle to condense multiplicity into a type of singularity with one name, which results in doing away with multiplicities. Within the movement, some multiplicities of endometriosis are to be prioritised. This results in a limiting of who is considered to have endometriosis (in a similar way to gynaecologists in Chapter 5).

I employ the term 'endometriosis movement' because the alternative terms such as 'Awareness Movement' and 'Support Group' do not capture the complexity of these patient-advocacy entities. While the endometriosis movement does reflect some need for increased awareness, it has been largely built on notions of decreasing the feelings of isolation experienced by women with endometriosis and their powerlessness both within the medical visit and before seeking help. Therefore, I argue that this movement is not just an awareness movement. Instead, it promotes 'sisterhood' in which women with endometriosis look to become more empowered and to gain a support system made necessary by the common suffering of those affected by the disease.

The endometriosis movement has three discernable structures: two outward facing and one facing inwards. Each external strand faces a different community: the general population and the medical community. The first strand is one linked largely to the idea

of endometriosis as a disease of women and one that utilizes slogans and visual imagery linked to feminist notions. This branch, like first-wave feminism, brings with it questions of how one defines the term woman and the critique that the term woman is linked only to Caucasian women, thus excluding women of colour. The second strand interacts with the medical system and offers a split between one group (The SHE Trust) more interested in complementary and alternative medicine, while its counterpart (Endometriosis UK) accepts more biomedical understandings of endometriosis while looking to influence policy and clinical care through first-hand experiential knowledge. The third strand faces inwards and is a movement for women with endometriosis led by women with endometriosis involving support through 'sisterhood'. The use of language and imagery linked to war[12] and to fighting is common within the endometriosis movement. Endometriosis and the stigma are seen as 'enemies to be battled' in a sustained way. There is a 'war' to be fought against the condition, against the silence, and sometimes against a medical system that largely ignores endometriosis as a serious condition.

II. Social Movements

Much of the literature on social movements is directed at 'collective identity,' the awareness of possessing interests, ideas and feelings similar to others who 'share the same stratum characteristics' (Gurin, Miller and Gurin 1980: 30 in Groch 1994: 371, Williams 1995, Melucci 1985). Collective identity has focused on the process of becoming a member of a social movement (Williams 1995) with members' views (after much re-negotiation and interaction) on the field of action converging and coalescing into a collective identity (Melucci 1985). More specifically, biosociality (Rabinow 1996) has been used to explain the collective identity of individuals with unifying biological features such as specific genetics or illnesses like neurofibromatosis or in this case endometriosis, with groups forming to share experiences and lobby on behalf of individuals with the condition. Such collective affiliations allow for legitimisation of experiences and knowledge (Brown 1992, Clark and James 2003, Sulik 2009),

[12] My participants use language linked to war, to battle, and to fighting here. I have also incorporated this type of language in my discussion of the endometriosis movement.

challenging of medical diagnoses (Sulik 2009 citing Borkman and Mann-Giddings 2008), reducing alienation and participation in social movements (Barker 2002, Sulik 2009). They also popularise illness narratives 'encourag[ing] the construction of a unified, though fluid illness identity' (Sulik 2009: 1061 – citing Barker 2002).

These notions of collective identity and biosociality assume that members of a movement have similar reasons for being a part of the movement, encouraging a focus on the potential singularity of the condition. Requiring a 'frame alignment' in which members have the same 'schemata of interpretation' (Goffman 1974: 21 in Snow et al 1986: 464) allows for one united ideological view within the movement itself. Several ideological 'frames' can co-exist at the same time, causing 'frame disputes' or conflicts regarding matters of interpretation (Benford 1993). Social movements may not be completely cohesive or unified (Benford 1993) and 'are rarely so consensual that they only offer one coherent "frame" at a time' (Williams 1995: 130).

While the notion of a 'frame-shift' or 'frame disputes' within a social movement has been discussed at length, it assumes a split from the original movement as opposed to the possibility of several ideological 'frames' simultaneously existing without necessarily being in conflict. I suggest the possibility that several facets of the same movement may exist together, which then creates another form of multiplicity. Thus with respect to the endometriosis movement, there are three facets, two external facing sub-movements, 'externally oriented' strands, and one internally facing or 'internally oriented' sub-movement, largely a mechanism of support for women with the disease (Hardon 2006).

A. Health Social Movements

Health social movements have been considered as collective challenges to public health and medical policies, as well as research practices by both formal and informal networks (Brown and Zavestoski 2004). Previous literature on networks by people living with specific medical conditions has considered their formation in response to

'pain and loss experiences,' with these negative experiences allowing for a collective identity to emerge (Jennings 1998).

Health social movements have been differentiated into health access movements which aim to establish 'equitable access to health care and improved provision of health care services' (Brown and Zavestoski 2004), and embodied health movements which are often used in the realm of contested illnesses with the goal of challenging established biomedical notions of aetiology, diagnosis, prevention and treatment and of increasing recognition and research on the condition (Brown and Zavestoski 2004). Others have suggested that health social movements can be divided into protest groups which are formed to fight a harm attributed to a human agent (for example medical errors), and health consumer groups which seek to 'promote and/or represent the interests of users … at a national level' and 'to capture [their] experiences' (Allsop et al 2004: 739). In addition, online health social movements have been thought to critique the biomedical system allowing sufferers to make sense of their own personal narratives, and allow for the formation of self-help groups which allow for empowerment of its members while challenging the medical system (Dumit 2006).

Previous studies of the endometriosis movement have focussed on online groups and blogs as mechanisms for espousing experiential knowledge over biomedical knowledge (Whelan 2007, Neal and McKenzie 2011) as well as for support and decreasing isolation (Griffith 2009). Whelan (2007) discussed the use of self-help literature to improve symptoms and Seear (2009c, 2014) discussed the increased personal responsibility and financial burdens placed on women with endometriosis due to such literature. To my knowledge, until my research, no others have written about this movement more broadly.

B. Women's Health Movements

More generally, Takeshita (2012) and Hardon (2006) have written about the women's health movement as a form of resistance against biopower and control of women's bodies through abortion rights or birth control. This approach has origins in the second

wave of feminist movements that aimed, in the late 1960s and early 1970s, to secure the right to abortion and contraception and expressed concern over patriarchal control over women's bodies especially within medicine (Hardon 2006). The first conference on this topic, the First International Conference on Women and Health was held in 1977 in Rome. It concentrated on matters related to breastfeeding, maternal health and environmental health. Subsequent meetings focused on reproductive rights of women under slogans such as: 'Population Control – No Women Decide' (1984 4th International Women and Health Meeting in Hardon 2006: 617).

Not only was the focus on reproductive rights, it was about reclaiming knowledge and power over one's own body, ultimately linking women's liberation to women's health. Thus the healthcare system became a battleground for second-wave feminism. There were calls to change the medical system, but also to ensure that women became stronger, more autonomous and increasingly self-assured (Kuhlmann 2009). However, the integration of feminist agendas into healthcare systems has not been consistent among countries; women's health clinics have been more prominent in the United States than in the Germany or the UK, for example (Kuhlmann 2009). In the latter two countries, structural integration of feminist notions into the health system have not been as successful (Kuhlmann 2009).

While women with endometriosis acknowledge the existence of social stigmas related to endometriosis and difficulties accessing care, it is not clear that the movement sees itself as a form of resistance to medical control, however. Nevertheless, I think it is helpful to consider the endometriosis movement as strongly linked, in its first outward strand, to feminism.

III. The Endometriosis Movement and Feminism

A. 'We Can Do It'

Figure 9.1
Poster of 'We can do it,' one of the images/symbols used in the feminist movement during World War II.

One of the main images used in the women's movement focuses on history that has been mistakenly thought to be entrenched in World War II and the role of women at that time: 'We Can Do It' was also erroneously known as 'Rosie the Riveter' (Figure 9.1). It is commonly thought that the poster represented a departure from the traditional role of women to stay in the home. Married women were then not only allowed but encouraged to take on crucial jobs that allowed the country to function while many men were off fighting the war. Or at least that was the myth! (Kimble and Olsen 2006)

Figure 9.2
Use of the "We can do it" symbol in a poster applied to women seeking political office.

This image, only known as 'We can do it' was created by J. Howard Miller, a graphic designer in 1943 for the company Westinghouse in the United States. It is purported to have hung for only two weeks in February 1943 (Lester 2014, Smithsonian 2016, Kimble and Olsen 2006) on Westinghouse factory walls with about 1000 copies produced. It was aimed at encouraging women working on the shop floor, most of whom were single, as opposed to the married women suggested in the myth, to increase productivity of war products (Kimble and Olsen 2006).

Despite this misunderstanding, the poster came back into use in a 1982 Washington Post Magazine Article presenting the recently made available poster in the United States National Archives and then again in 1985 in a U.S. News and World Report. It continues to be mistakenly linked to the place of women in War World II (Sharp and Wade 2011). It is commonly used as a feminist symbol (Valenti 2011, Sharp and Wade 2011) in 2nd wave feminism, as a heroine in children's stories and on lunch boxes joining Batman and Wonder Woman as superhero (Kimble and Olsen 2006). The well-established link between this poster and feminism comes from an understanding of the

poster outside its true context, together with an 'anachronistic recognition of female empowerment' (Kimble and Olson 2006: 550). More recently, it has been used on a stamp, and as a symbol of support for both Hillary Clinton and Sarah Palin in the 2008 election cycle in the US (Sharp and Wade 2011) as seen in Figure 9.2.

This symbol has been re-purposed for chronic conditions affecting women, such as breast cancer and now endometriosis. Figure 9.3 is an example of this re-appropriation of the feminist symbol for the 'endometriosis cause'. It modifies the original poster to add 'Endometriosis Awareness' on the bottom with a yellow background, the Slogan 'Fight Like a Girl', and the yellow ribbon symbolic of Endometriosis Awareness on the collar of the shirt.

Figure 9.3
Utilization of the 'We can do it' symbol in endometriosis.

B. Wonder Woman

The character Wonder Woman ('Princess of the Amazons') is seen frequently online on endometriosis related images. It is seen as symbol of both strength and sisterhood. Marie posted Figure 9.4. She explained: *'Today hurts, but I know I'm not alone'.*

Figure 9.4
A poster of wonder woman as a symbol of strength and sisterhood posted by Marie.

Wonder Woman, a comic book character and then a television character in the late 1970s, was created in 1941 by the Harvard-educated psychologist William Moulton Marston in collaboration with comic artist Harry Peter. They intended Wonder Woman to be 'a character with all the allure of an attractive woman but with the strength also of a powerful man' (Daniels and Kidd 2000 cited in Delaney 2014: 2) and for the comic to perform the specific role of 'psychological propaganda for the new woman who should … rule the world' (Daniels and Kidd 2000 cited in Delaney 2014: 2).

In the 1940s, Wonder Woman represented a new type of woman, a shift to one who was more independent and had more strength, but who retained her beauty and femininity (Delaney 2014). The comic book included stories of the 1848 Seneca Falls convention on women's suffrage, the first meeting of its kind and the beginning of the women's rights movement in the United States (Lepore 2014a). Wonder Woman was used as the

first cover of Ms. Magazine by Gloria Steinem[13] (Lepore 2014b), but this time as a critique of the lack of forward movement, as women had gone back into the home after World War II (Gloudeman 2014).

Thus, the utilization of Wonder Woman as a figure representative of the endometriosis movement shown for example in Figure 9.5 below suggests a link to feminism. Figure 9.5 shows Wonder Woman in her classic position with her fists by her side standing ready to fight, with stars next to her, and the words 'Fight Like A Girl' in front of her. The image is a call for Endometriosis Awareness to battle like Wonder Woman with supernatural powers.

Figure 9.5
Use of the wonder woman image to represent the endometriosis movement and its link to endometriosis.

C. Marilyn Monroe

Women with endometriosis post many images of Marilyn Monroe on awareness posters. She was a famous actress who suffered from endometriosis. She may have she died of an overdose of painkillers used to treat the condition (Fraser 2008). She was apparently unable to have children and suffered several miscarriages attributed to endometriosis (Fraser 2008). Like 'Rosie' and Wonder Woman, Marilyn Monroe has

[13] Gloria Steinem is well known as a feminist organizer in second wave feminism and the founder of Ms. Magazine, Women's Action Alliance and National Women's Political Caucus and Co-founder of Women's Media Center and Voters for Choice (http://www.gloriasteinem.com/about).

been used as a symbol of feminism with Gloria Steinem stating that 'her experiences were ones that feminism often speaks out on: sexual abuse, sexual victimisation, [and] a mother's madness' (The Guardian May 29, 2001: 2).

This viewpoint is echoed by Erin Johansen, a third-wave feminist and editor of the website www.girlchick.com who explained that 'a lot of young feminists see her as a sort of martyr for modern feminism, as a shocking example of how a woman can be torn apart by the greed, lust and coercion of men in their life' (The Guardian May 29, 2001: 2). In addition, Marilyn Monroe is said to have recognized the oppression of women and was angry at the 'hegemonic masculine studio system that had used her, limiting her salary while making millions from her films' (Banner 2008: 21). The use of her image in Endometriosis Awareness posters online suggests again a link of the movement to feminism. She is a powerful choice, a feminist symbol, and the ideal of femininity, representing an example of the struggle with endometriosis.

Figure 9.6
Women with endometriosis often post images of Marilyn Monroe. This image was posted by Janet.

Janet, in posting Figure 9.6, explained:

> *Possibly one of the most famous faces in the world, certainly as a female face. Known to be the epitomy of beautiful yet tarnished with scandal and gossip. Marilyn was 36 when she died from what its believed to be an overdose on pain killers. I am 35. What people don't know is that she had Endometriosis and suffered terribly with pain, having ectopic pregnancies and her dependancy on pain relief was in part because of her Endometriosis.*
>
> *She painted on a smile, she tried so hard to live life to her fullest but as the lyrics say:* ***Loneliness was tough***
> ***The toughest role you ever played***
>
> -O

Marilyn Monroe remains a symbol of feminism but also represents the epitome of 'femininity' despite her struggles with endometriosis. She becomes something of an ideal for other women with endometriosis who often speak of their lost femininity. She is the ultimate example of the 'mask of health' with her ability to keep her smile and to look as though she had overcome loneliness. Figure 9.7 tells us, 'Even the brightest stars hold dark secrets of pain & suffering caused by endometriosis'.

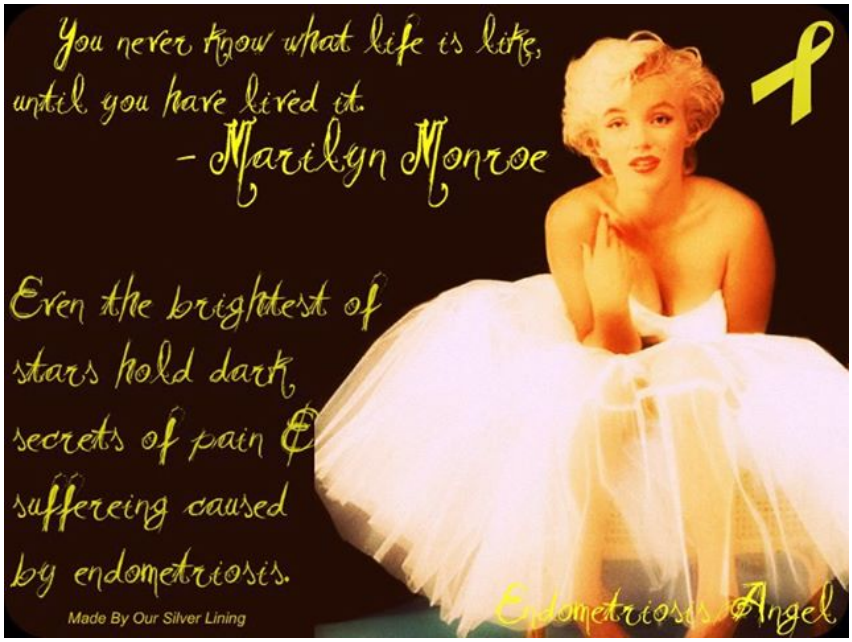


Figure 9.7
An example of a posted picture of Marilyn Monroe which alludes to her own struggle with endometriosis.

D. The Mad Pants Tea Party

I attended the Mad Pants Tea Party that took place on the 27th of September, 2014 in a village in the North East of England. It was an event planned with the goals of increasing awareness about endometriosis and of raising funds for Endometriosis UK. Its association with Pink Pants reaffirmed the link between the endometriosis movement and women's health to feminism.

> *I walk into the village hall: all the tables are covered in pink table clothes, the women from the support group have on the Endometriosis UK T-shirts (white with the pink logo) and 'pink pants' on top of their trousers. Lori, Jackie and Mary, members of the support group, comment on how surprised they are about how many people have turned up and how many men came. They explain, very excitedly, that there are cakes, cupcakes, tea, coffee, and books for sale, a quiz coming up around endometriosis including a music round and a round on famous women with endometriosis, and ask me if I would be willing to man (sic) the information booth.*-F

This 'mad pants tea party' while a fundraiser for Endometriosis UK, also placed endometriosis as a disease of women through its pink colour, and through the music where the songs were as Lori put it *'powerful songs, by women'*-F and the examples of women with endometriosis in the quiz included Hillary Clinton, Whoopi Goldberg and of course Marilyn Monroe. Even the poster for the Tea Party, Figure 9.8, was pink with three women dressed in pink, with pink flowers decorating the poster. The link to women is unmistakable.

Figure 9.8
Poster of the 2014 Mad Pants Tea Party, a fundraiser for Endometriosis UK.

E. Fight Like a Girl

The slogan 'Fight Like a Girl' is one found commonly online with regards to Endometriosis Awareness as seen in Figures 9.3 and 9.5 above. While it is unclear where the expression originated, it is likely a play on the saying 'like a girl' which has historically been used with intent to demean others. Classic examples include 'you run like a girl', often used to criticize men in sports settings; or 'don't cry like a girl', an effective manner of dismissing an unhappy woman (Greenfield 2014). The idiom 'like a girl' has connotations of 'someone who's useless, weak, laughable perhaps', and the term 'girl' has become 'a derogatory, throwaway remark, an insult' (Greenfield 2014). Hashtag #LikeAGirl was started in 2014 with a video made by the company Always. It examined, in the first half of the video, the use of the phrase as an insult; in the second half, it suggested that the term ought to be reclaimed as positive. 'Why can't run like a girl also mean win the race?' it asks us (Youtube video 2014). Since 2014, the saying 'like a girl' has become a slogan effectively re-appropriating the term in a positive and feminist frame in which 'like a girl' is now linked to notions of power and strength.

In addition, the term 'fight like a girl' has been used as a title for several feminist texts (Bevere 2006, Gervasi 2007 and Seely 2011). It appears to be associated with several other movements linked to women's conditions, such as ovarian cancer and breast cancer. However, there have been links to other conditions that do not primarily affect women such as lymphoma and HIV (Fight like a girl 2016).

The slogan 'fight like a girl' when used on endometriosis-related posters or images is often linked to boxing. For examples, see the tattoo shown in Figure 9.9 and fists (Figure 9.11). From time to time women are depicted wearing a yellow[14] boxing robe as seen for example in Figure 9.10. The link to boxing highlights the notion of physical contact and impending violence. Thus, the phrase 'fight like a girl' takes on new

[14] The colour of the endometriosis movement is yellow. The reason for this choice remains unclear, except for the one explanation given to me by several research participants, that *'pink is already taken'* by breast cancer.

meaning. The 'girl' now becomes strong, powerful, and ready to fight and perhaps defeat her opponent. The link with violence and the fight is more evident.

Figure 9.9
Use of the slogan 'Fight like a girl' in an endometriosis-related poster showing a woman ready to box.

This slogan finds its way onto many posters of Endometriosis Awareness and also on merchandise such as t-shirts, phone covers, pins, and jewellery. Thus, the slogan takes on a business dimension. While you can buy these items from several websites, the proceeds are rarely directly linked to the movement, with only limited periods of time when up to 50% of the proceeds are donated to the cause.

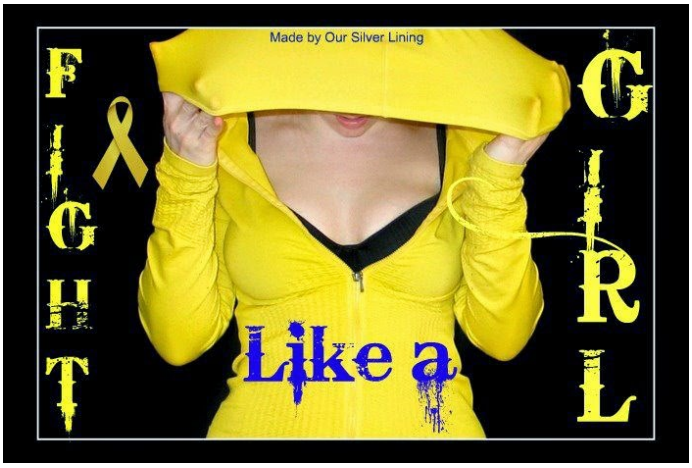


Figure 9.10
Image of a woman wearing a yellow boxing robe. Yellow is the colour used in the endometriosis movement.

Figure 9.11
Ready for the fight: 'The fight like a girl' symbol in yellow superimposed on a fist.

F. The Endometriosis Warrior

The rhetoric of war is further illustrated through the use of the phrase the 'endo warrior'. Images online show women as 'endo warriors'. For example, Figure 9.12 depicts a woman in a helmet, with yellow ribbons on her face and holding a sword. Her stern look portrays both a certain resolve and sadness as the makeup around her eyes

resembles tears. She appears ready to go to battle and perhaps reminds us of the Amazons (Greek mythological female warriors).

Figure 9.12
Figure of the endometriosis warrior with a helmet and a sword.

War has been traditionally perceived largely as a domain dominated by men where women have served as victims, prizes or spectators (D'Amico 1996). Radical feminists have understood the notion of the woman warrior as 'representing women's potential for power, as lingering evidence of an ancient matriarchy or woman-centered and woman-governed society' while embracing it as a symbol of sisterhood and solidarity (D'Amico 1996: 380). Katie, a woman with endometriosis writing online, bolstered this link to feminist notions:

> *For all my fellow warriors:*
> *"WOMAN! WO-MAN! WOOOAAH-MAN!"*
> *Depending on what country you were in, you would have been made aware that it was International Woman's Day recently.*
> *But did you know that March is also ENDOMETRIOSIS AWARENESS MONTH?*-O

The term 'woman' becomes remarkably important here, with us imagining Katie yelling 'woman' with strength and conviction that together the warriors will defeat their enemy. She linked Endometriosis Awareness Month directly to International Women's Day,

which ‘celebrates the social, economic, cultural and political achievement of women’ (International Women’s Day 2016).

The use of such obviously military language here should be highlighted. The tenacity of the disease, the difficulty in establishing effective relationships with caregivers, and the significant impact on everyday functioning create a state of mind in the woman with endometriosis that can be readily characterised as frustration and often times anger (as seen in Chapter 8). This all contributes to a sense that there is a something to be fought, that women with endometriosis are warriors.

G. Million Woman March for Endometriosis

The first Million Woman March for Endometriosis was held on March 13, 2014 at 53 locations around the world, including Washington D.C. and Hyde Park, London, UK. I attended the march in London, attended by approximately 150 people (Endometriosis UK MWK FAQ 2016), as part of fieldwork for this thesis. The attendees can be seen in Figures 9.13 and 9.15. Each group, from each location, was termed a ‘Team’ with Team UK explaining that its main goal was to heighten awareness of endometriosis. But the march also sought to increase empowerment by uniting women and their supporters and to enhance education and training of healthcare professionals. In addition, it emphasized the need for research funding from the government for both a cure and non-invasive diagnostic tests (Endometriosis UK MWK FAQ 2016).

The UK Team was dressed in Endometriosis UK t-shirts (white with a pink logo), and marched around Hyde Park for approximately three hours. There were few onlookers; those people who were around appeared to be there because it was a lovely, sunny day. Those marching were for the most part women with endometriosis. But mothers and partners, including a handful of men, were also present. Patricia, for example, attended because her daughter was unable to march, feeling ill that day and struggling to cope emotionally with her six-month-old diagnosis. Patricia explained that she felt powerless to help her daughter who was in her early twenties and attempting to finish university.

Attending the march helped her to feel that she was *'doing something*' and made her '*understand what my daughter is going through'*-I.

Figure 9.13
Attendees at the 2014 First Million Woman March for Endometriosis.

Participants were asked to write on blank pieces of yellow paper, for the benefit of the onlookers, their reasons for marching. Figure 9.14 shows two women with endometriosis with their posters. Lisa, the woman on the left, explained: *'I am Marching for Endopendence # for all who aren't here but know!'* Marjorie wrote, *'I am marching to find a cure so our daughters and g/daughters won't have to suffer like millions of women already have!'*. Others spoke of stigma, lack of research, long waits for diagnosis and not being believed by the medical community, as reasons for attending the march.

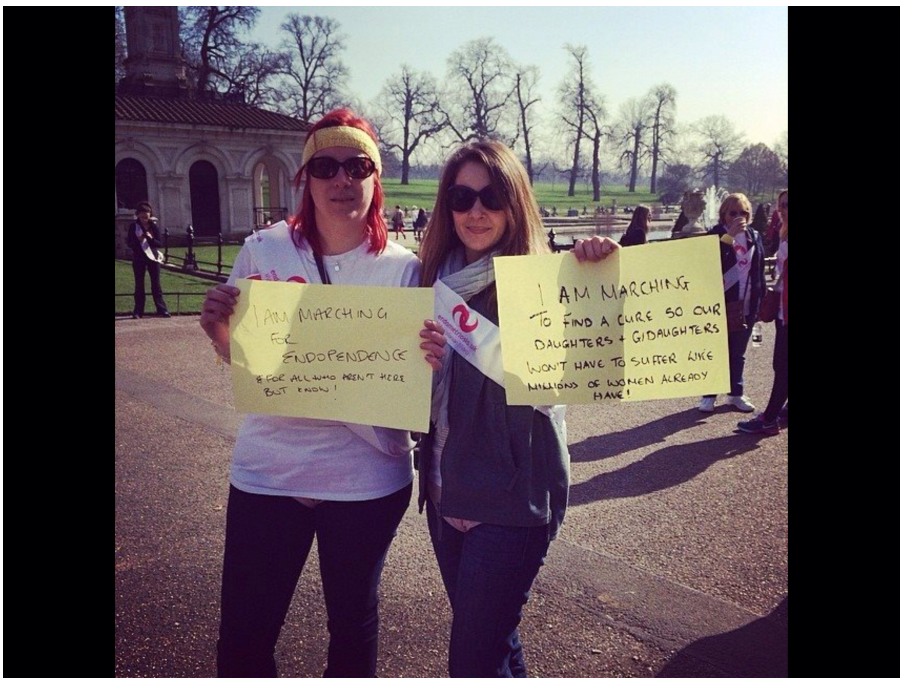


Figure 9.14
Two participants at the 2014 First Million Woman March for Endometriosis holding yellow sheets of papers on which they had listed their reason for marching.

Figure 9.15
Attendees at the 2014 First Million Woman March for Endometriosis.

The name 'Million Woman March' was a likely nod to the U.S. 'Million Man March' of October 16, 1995 led by Louis Farrakhan, with the objectives of placing 'the issue of

Black suffering back on the nation policy agenda' (Nelson 1996: 10), on the one hand, and on the other hand to provide an opportunity for African American men to publicly 'repent of their transgressions against Black women, Black children and Black communities' (West 1999: 92). That march was held for Black men, with the suggestion the women stay home but avoid patronising White businesses on the day. It was largely criticised for its gender politics as utilising a 'simplistic inclusion/exclusion model' (Alexander-Floyd 2003:194). The subsequent Million Woman March held on October 25, 1997 in Philadelphia, USA, also limited its attendance, this time to Black women largely in response to the original gender exclusion (West 1999, Alexander-Floyd 2003).

Thus, the name 'Million Woman March' for Endometriosis strongly implied that its attendance should be circumscribed with only women participating. This was supported by the following description given by Endometriosis UK attached to their poster, Figure 9.16:

Figure 9.16
Poster announcing the 2014 First Million Woman March for Endometriosis. Poster designed by @Kaye Sedgwick

> Across the globe, millions of women will be taking part in a peaceful demonstration to raise awareness of endometriosis and the plight of those who suffer from the condition. It's a chance for everyone affected by endometriosis to come together and make their voices heard! The official UK Million Woman

> March and will take place in London. Join us and let your voice be heard! (Endometriosis UK) -https://uk.pinterest.com/endometriosisuk/the-million-woman-march-for-endometriosis-uk/ accessed April 22, 2016

The explanation of Figure 9.16 speaks of the millions of women who took part in a demonstration to increase awareness of endometriosis and the 'plight of those who suffer from the condition'. The implication here is that only women should attend and that only women suffer from endometriosis. This very issue is one that proved to be contentious online with many discussions focused on how to define women, whether there are assumptions about sexuality with heterosexual women being prioritized over others, and whether male partners should be included as endometriosis may affect them as well, albeit in a different way. Fast-forward two years to the march from 2016, and the name has now changed to EndoMarch or the Endometriosis Worldwide March perhaps specifically for this reason. The website explains:

> Please note that our nonprofit is still listed under our former name, 'Million Women March For Endometriosis.' However, we applied for a name change, which will soon be reflected in the official IRS system. http://www.endomarch.org/mission-statement/ accessed 2016

IV. Addressing Diversity within the Endometriosis Movement

Similar to the history of the women's movement, with its struggles to include minority women as well as its failure to question the gender binary, the endometriosis movement, despite its collective identity through biosociality, is now experiencing similar frame-shifts, with calls to be more inclusive on a multi-ethnic level and to dispel the notion of endometriosis as solely a white woman's disease. The definition of 'womanhood' confines who can have endometriosis to a relatively narrow group of people (like the gynaecologists in Chapter 5). The multiplicity of endometriosis is itself again bounded leaving only certain versions of endometriosis as legitimate. The category endometriosis becomes available to only certain people.

A. Which women?

Overall, the visual imagery around the endometriosis movement lacks any representation of women of colour. While not an official policy, such groups have been largely left out of any rhetoric about the condition. I only found two pictorial representations of minority women (See Figures 9.17 and 9.18) among the many hundreds of images I reviewed online. This is also the case with research on endometriosis where women of colour are largely left out despite the fact that endometriosis support groups exist in the Caribbean (Barbados, Jamaica, and Trinidad and Tobago), different African countries, and in Iran. There are also Latina endometriosis associations (Figure 9.17).

Figure 9.17
One of the few representations of minority women – Latina women with endometriosis.

The few images I found including Figure 9.17 and 9.18 were all from one website in the UK. This website is not officially associated with Endometriosis UK or the other UK endometriosis movement, the SHE Trust. It was founded by one woman who has created her own images and has represented minority women as women with endometriosis with Figure 9.18 for example, showing three women, one with blonde hair, one with brown hair and a black woman with black hair each with different colour shoes on and remarkably the yellow shoes given to the minority woman.

Figure 9.18
Image of women with endometriosis from different racial backgrounds.

Similarly, Figure 9.19 shows a Muslim woman in a yellow Hijab with similarly matching yellow shoes.

Figure 9.19
Representation of a Muslim woman with a yellow Hijab.

Overall the lack of such visual imagery suggests that endometriosis remains a condition of Caucasian women and these are the 'women' who are considered as both a part of the movement and worth fighting for within the movement.

B. How Do We Define Women?

Debates regarding whom to include in the movement are many and complex, with the notion of endometriosis as a disease of 'women' remaining at the forefront here. The critique of the endometriosis movement as conforming to the gender binary can be seen online with several people coming out against the notion of endometriosis as a woman's disease. Endometriosis warriors are no longer just women or just sisters. Instead, there are non-binary endo warriors as Figure 9.20 illustrates.

The movement, if dedicated to women, leaves Leslie, who posted figure 9.20, feeling forgotten. For Leslie, it is not gender but reproductive organs that makes someone an Endo Warrior.

> *So this post goes out to all the Genderqueer/Non-Binary/Trans* individuals who like me feel forgotten by a movement that forgets we can have the same disease as those who are cisgender. …*
>
> *Please remember it's our reproductive organs that make us Endo Warriors, not our genders. I have endo and am genderqueer, neither male or female but somewhere in between. Trans* Men with endo are warriors too.* – O https://bloominuterus.com/2015/10/ Accessed April 23, 2016

Figure 9.20
Endometriosis also affects non-binary individuals.

Not only does this criticism apply to the endometriosis movement, it also applies to research and to any support one might receive as Nat explained on another website.

> *:/ I really wish there was more support for trans men/nbies with endometriosis. I feel so alone. Literally all the campaigns for awareness/research/support focus entirely on women. Endo warriors are not all women.*
> -O http://second2last-in-line.tumblr.com/post/122001672159 Accessed April 23, 2016

Kelly wants to include sexuality in this discussion, suggesting that endometriosis research is often assumed to be relevant to 'heterosexual women' alone. In addition, Kelly feels that biomedical research links vaginas, uteruses and ovaries with 'womanhood' and therefore endometriosis with women.

> *I myself am genderqueer, and there are many people with endometriosis who are not women (e.g. men and other non-binary people like myself). I have no intention to erase these people (and myself) from this article, however the majority of people who suffer from endometriosis are women and in our cissexist and binary loving society the scientific research that is done focusses on cis women (women who were assigned women at birth and found this*

> *assignation felt right when they were older) and also (wrongly) conflates ovaries, uteruses and vaginas with 'womanhood' and women.*-O http://kedwardshuolohan.weebly.com/blog/the-endo-silence-ending-the-silence-around-endometriosis accessed April 23, 2016

This notion was felt to interfere with medical visits, leaving many non-cis women and trans men uncomfortable in discussions with gynaecologists who are not at ease discussing these topics and who often assume that all non-cis women act and want the same things out of life such as potential children.

> *It's a major problem when you have many non cis women and trans men that are fearful, fed up and annoyed with going to the ob gyn because of the misunderstandings, hetero-normative questions and just simply not listening to understand the unique issues that we experience. What's worse is that many avoid going at all to avoid the hassle and its time that health care providers realize that endometriosis effects a diverse group of women with different experiences, orientations, identities, needs and not just the hetero cis women.*-O http://www.centerforendometriosiscare.com/march-is-endometriosis-awareness-month-real-stories-from-real-experts/ Accessed April 23, 2016

V. Frame-Shifts, the Medical Community and the Endometriosis Movement

The second 'outward facing' part of the endometriosis movement looks to address the medical community. In this perspective, the rhetoric draws less on feminism than on experiential knowledge and illness narratives. Here, then, is another 'frame-shift' in which one endometriosis association in the UK splits into two. I was told by my research participants that this was due to a philosophical divide in which one group, now known as Endometriosis UK, was interested in staying linked to the medical community and to possible medical treatments while the other faction, now called the Endometriosis SHE Trust, was focused on environmental causes of endometriosis and on treatment through complementary and alternative medicine. This split is now quite obvious with both websites clearly having different aims and objectives. This parallels the frame-shift seen in the breast cancer movement with one subgroup interested in environmental causes for breast cancer and the other focussing on more biomedical notions of breast cancer (Klawiter 2004).

The SHE Trust was founded in 1999 by a multi-disciplinary team of 'a retired GP Tutor/Trainer, a retired Senior Nurse Practitioner, a Nutrition Consultant and a Health Visitor' (Shetrust 2016). The goal of the organisation was and remains to 'offer help, information and support to women with endometriosis and everyone else interested, to be able to make informed choices about conventional, nutritional and complementary therapies available' (Shetrust 2016). In addition, on the first page of the SHE Trust website, there is a poll asking: 'Have you tried any complementary therapies for your endo?' (Shetrust 2016).

Endometriosis UK presents the disease through a joint biomedical and illness narrative lens. Therefore, and in contrast to the SHE Trust, it has successfully been included in strictly biomedical arenas such as the formation of NICE guidelines, and in the development of leaflets on endometriosis distributed in different gynaecology clinics. However, as we saw in Chapter 4, the views of women with endometriosis on issues such as delayed diagnosis and what I am calling the a-diagnostic category remain largely discounted by the NICE guidelines. The illness narrative that the movement aims to project to the medical system thus remains largely secondary and incomplete.

Similarly, the use made by Endometriosis UK of pamphlets on endometriosis in gynaecology clinics may not achieve its goal of allowing women with endometriosis to access information more easily. Consultants in this study openly acknowledged that to teach patients about endometriosis was difficult. They reported feeling unsure of how to teach something so complicated, with so many unknowns. One explained, *'It is easiest to teach retrograde menstruation isn't it? But that doesn't cover everything does it?'*

Many registrars also appeared unwilling or unable to make decisions about endometriosis patients on their own. Instead they would consistently ask the consultant about what he or she would do in this situation both in terms of treatment and in terms of what to say to the patient. Thus, explaining endometriosis to patients left them feeling uncomfortable. In the example below, an excerpt of field-notes from my time in

the gynaecology clinic, pamphlets provided a way out of this difficult situation allowing gynaecologists to avoid the discussion altogether.

> *It is an endometriosis clinic. We are in the last room at the end of the hall. The patient is a new patient at the clinic/hospital complaining of pelvic pain for several years. She is a relatively quiet patient – who is unassuming and is simply asking nicely for someone to help her with her pain.*
>
> *GP-trainee/registrar to patient: 'So there is a chance that you may have endometriosis. We can therefore do one of two things: either 1. Put you in for a keyhole surgery (laparoscopy) or 2. Treat you medically as if you have endometriosis and see if that helps.*
>
> *Patient: well I'd prefer to see what is going on. So let's do the surgery. But I was wondering if you could tell me more about what is it again?*
>
> *GP-trainee/registrar: I will go see if I can get a leaflet for you.*
>
> *Patient: Are there any leaflets?*
> *GP-trainee/registrar: No, no we do not have any. OK perhaps Véronique can point you to information online?*
>
> *Patient: Is there any way you can explain it a bit to me now as I really do not know anything about this disease and I'm a bit scared now.*
> -F

Thus, having leaflets became a way out of explaining the disease to patients and also a way out of learning the information as doctors and medical professional. So, while the apparent goal of Endometriosis UK in providing these pamphlets is one of giving more readily available information on endometriosis both biomedically and through a narrative perspective, it may lead women with endometriosis to have less access to information directly from their medical professionals.

VI. The Inward Facing Movement

The third facet of the endometriosis movement is one of internal and mutual support for women with endometriosis. This remains often more one-to-one with women coaching each other either online or in person with the goal of providing support and helping

other women navigate the medical system through implementation of control strategies. This 'internal' system is one that is for women with endometriosis by women with endometriosis. In contrast to the two other facets of the endometriosis movement, this one is not meant for others. Instead, it is a form of biosociality (Rabinow 1996) that allows for decreasing isolation, the formation of a 'sisterhood' and the encouragement to speak and 'break the silence'. Here the themes from previous chapters come to the forefront with talk of stigma, suffering in silence, isolation, use of control strategies, and support through sisterhood. Because I have spoken about many of these issues previously, I will focus on discussing Support and Sisterhood here.

A. Decreasing Isolation

A main goal of the inward movement is that of decreasing the sense of isolation experienced by women with endometriosis. This was accomplished through several mechanisms, including in-person and online support groups, and images posted online addressing this issue. Figure 9.21 depicts a yellow ribbon with the word Endometriosis. Angelica, who drew Figure 9.21 and posted it, explained:

> *I created this a while back on the blank side of a notebook. The words around the ribbon read (from bottom left side) "We Are Not Alone! Many years of pain, discomfort, lack of sex, feelings of being useless, losing friendships or not going out, depressed, want to end it ALL?!!, sad, Loved, Angry, Tired, Happy, Fun, Down, Scared, Need understanding!! Strong!"*-O

Figure 9.21
An image created by Angelica to emphasize the need to fight isolation.

Fighting the isolation becomes very important both through these images stating '*We Are Not Alone!'* and through in-person meetings. In the support group I attended, for example, it was not uncommon for women to invite other women to call them, email them, or otherwise contact them if they felt the need. This was done through the leader of the local support group who offered her help to all, and through individual members of the support group who would also offer 'an ear', often explaining: '*that is what we are here for'* or *'we have all been there'*-F. In addition, the local support group also ran an online forum where women might contact each other for help if needed. While this method was rarely used, it was certainly there as an option. Some people used it between meetings.

Endometriosis UK also provides a helpline that women with endometriosis can call with any problems. To volunteer for this help-line, there is training that one must accomplish. 'Whether you've just been diagnosed, have questions about treatment options or would just like someone to talk to, you call our free confidential endometriosis Helpline' – explains the Endometriosis UK website (Endo UK Helpline 2016). However, the helpline appears to be specifically focused on support as the quotation used on its website speaks of 'emotional scars' and of the Helpline giving Elaine, the woman who called,

> *...strength to own my condition, rather than let it own me.*

I know of no participants who used this phone line, though some might have preferred not to discuss what is, after all, a confidential service.

B. Sisterhood

The term 'sisters' or 'sisterhood' came up often, reinforcing the notion of a familial status amongst the women, while again solidifying endometriosis as a condition solely of women. This 'sisterhood' is thought to function as a form of support contributing to decreasing the isolation as seen in Figure 9.22. This letter, to an 'unknown teenager' from an 'unknown sister', speaks of the struggles of pain and of worrying about one's future while also acknowledging the positive effects. It also seeks to empower by focussing on the body as one's own and on the ability to ask questions of one's doctor.

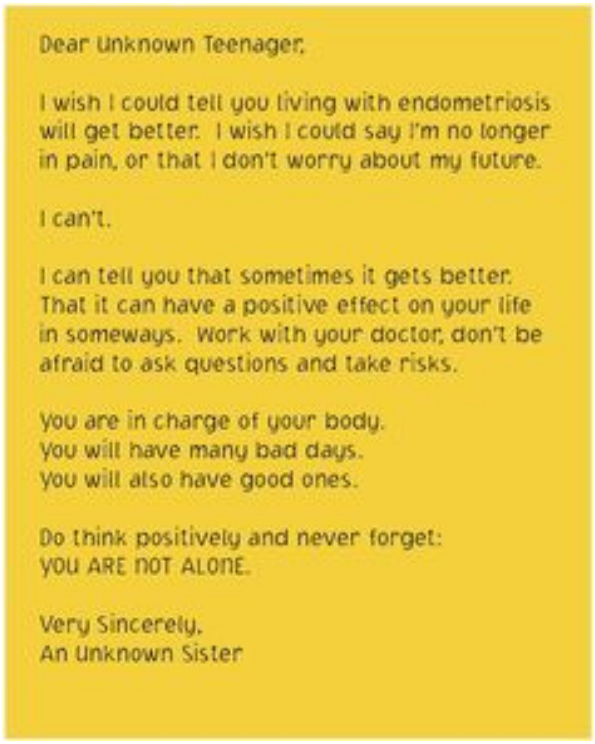


Figure 9.22
Letter to an unknown teenager posted by a woman with endometriosis to describe the struggles of pain.

While these words link clearly to notions of frustration, chronic anger and disappointments that fuel the belligerence women with endometriosis feel, it is the last line of the letter that resonates most strongly: 'YOU ARE NOT ALONE'. As indicated in Figure 9.23, there is a sisterhood, 'a clan of sisters, of warriors in our own right, standing strong together in the fight of our lives'. The sense that they are war together, linked through a sense of biosociality, prevails.

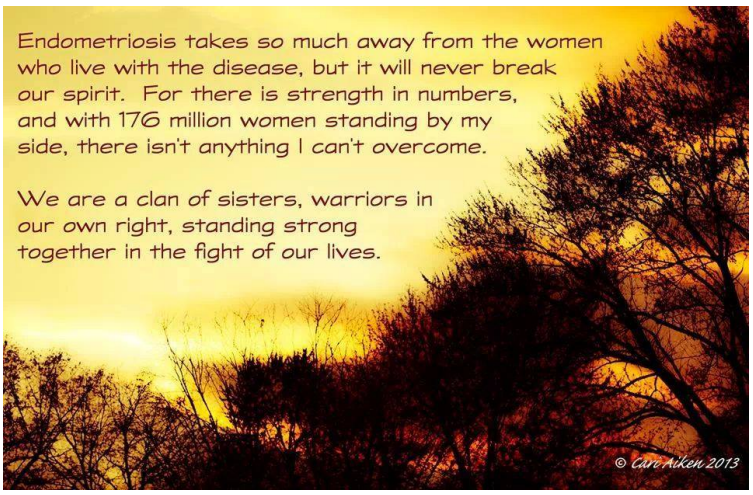


Figure 9.23
The sisterhood of endometriosis.

C. Breaking the Silence

Endometriosis UK places significant emphasis on the notion of suffering in silence. It attempts to break taboos and allow more women to recognize that they too may have endometriosis. With posters like Figure 9.24 and Figure 9.25, Endometriosis UK aims to reach women who do not yet have a diagnosis.

Figure 9.24
Endo UK poster designed to reach out to women who have not yet received a diagnosis.

Figure 9.25
Endometriosis UK poster designed to reach out to women who have not yet received a diagnosis.

Figure 9.26
Words to express endometriosis - There is no need to suffer in silence.

Figure 9.26 is an image linked to an Endometriosis UK campaign focused on the theme of suffering in silence. The request explained:

> Tell us in one word how endometriosis makes you feel. We believe that no woman with endometriosis should suffer in silence. Help us shout about the true impact of endometriosis. Take a photo of yourself holding your word, and send it through to us. Your word, combined with powerful words from others will help show exactly how it feels to have endometriosis. https://uk.pinterest.com/endometriosisuk/whats-your-word/ accessed April 12, 2016

Figure 9.26 depicts seven women with endometriosis who have chosen a word that they associate with endometriosis. The words include Tired, Ignored, Worn Out, Empty, Confused and Anxious. This campaign remained internal to women with endometriosis because these images appeared on endometriosis-linked websites visited mostly by people who already knew about the condition.

VII. Three Sub-Movements United to Fight The War

The three facets of the endometriosis movement all come together to 'fight a war'- such is the language and imagery used by my research participants. The notions of 'endo warrior' and of 'fighting like a girl' suggest a battle that is being waged by women with endometriosis. This military language defines the existence of an enemy and a struggle. But what is this 'war,' this 'battle' they are fighting? It is multi-faceted, with women speaking of a fight against endometriosis, a fight against their own bodies, a fight for an earlier diagnosis, a fight to be believed by medical practitioners, and a fight to have their voices heard.

Abby, who posted Figure 9.27 explained that the battle is against the disease.

> *[W]e ARE warriors because this disease - it IS a battle, something outsiders don't even realize. Sometimes we feel like we are winning, sometimes we feel like we are losing...but at the same time, wearing this makes me feel proud that I've battled something as horrible as endo and survived*.-O

For her, having endometriosis places women as warriors. The battle is largely hidden from those who are outsiders. It is one in which victory seems elusive, where winning or losing is not permanent, and where survival is something to be proud of and commemorated, in this case through a bracelet.

Figure 9.27
Picture posted by Abby. She proudly shows her "endo-warrior" bracelet.

Figure 9.28 also speaks of this 'battle within', this fight against the pain, but one that can be fought with support from others.

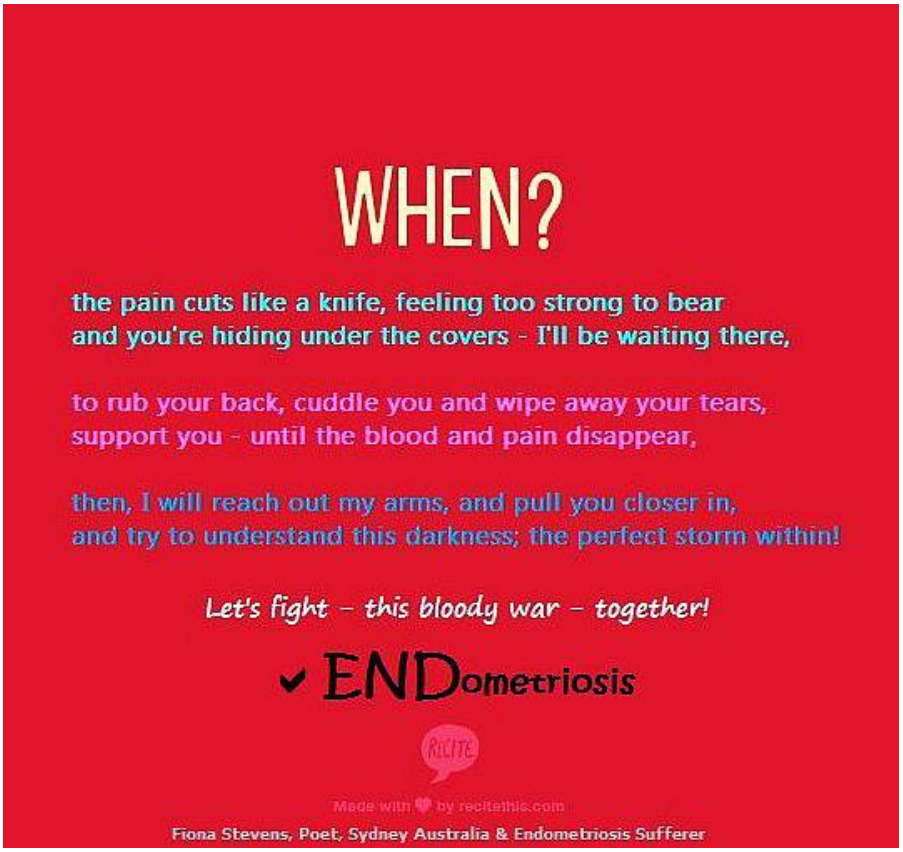


Figure 9.28
A description of the battle within.

However, the 'war' is not just internal for these women but also about creating awareness, decreasing times to diagnosis, decreasing any 'suffering in silence' and of course fighting against notions of 'It's all in their head'. Endometriosis is, according to a self-proclaimed endometriosis warrior Rachel:

> *A horribly misunderstood disease that affects 1 in 8 women worldwide. It can range from mild to life ruining! It takes an average of ten years to diagnose as it is not detected by standard testing. Many women end up with severe depression or taking their lives because they are told it's all in their head. IT'S NOT.*
>
> *For too long it has gone over looked, leaving many women devastated with nowhere to seek help. We aim to make our voices heard.*-O

The 'war' is about creating space for women to seek help and for their voices to be heard. Thus Rachel wrote her own poem titled 'The Fight' about her struggle with endometriosis, seen in Figure 9.29. She explains:

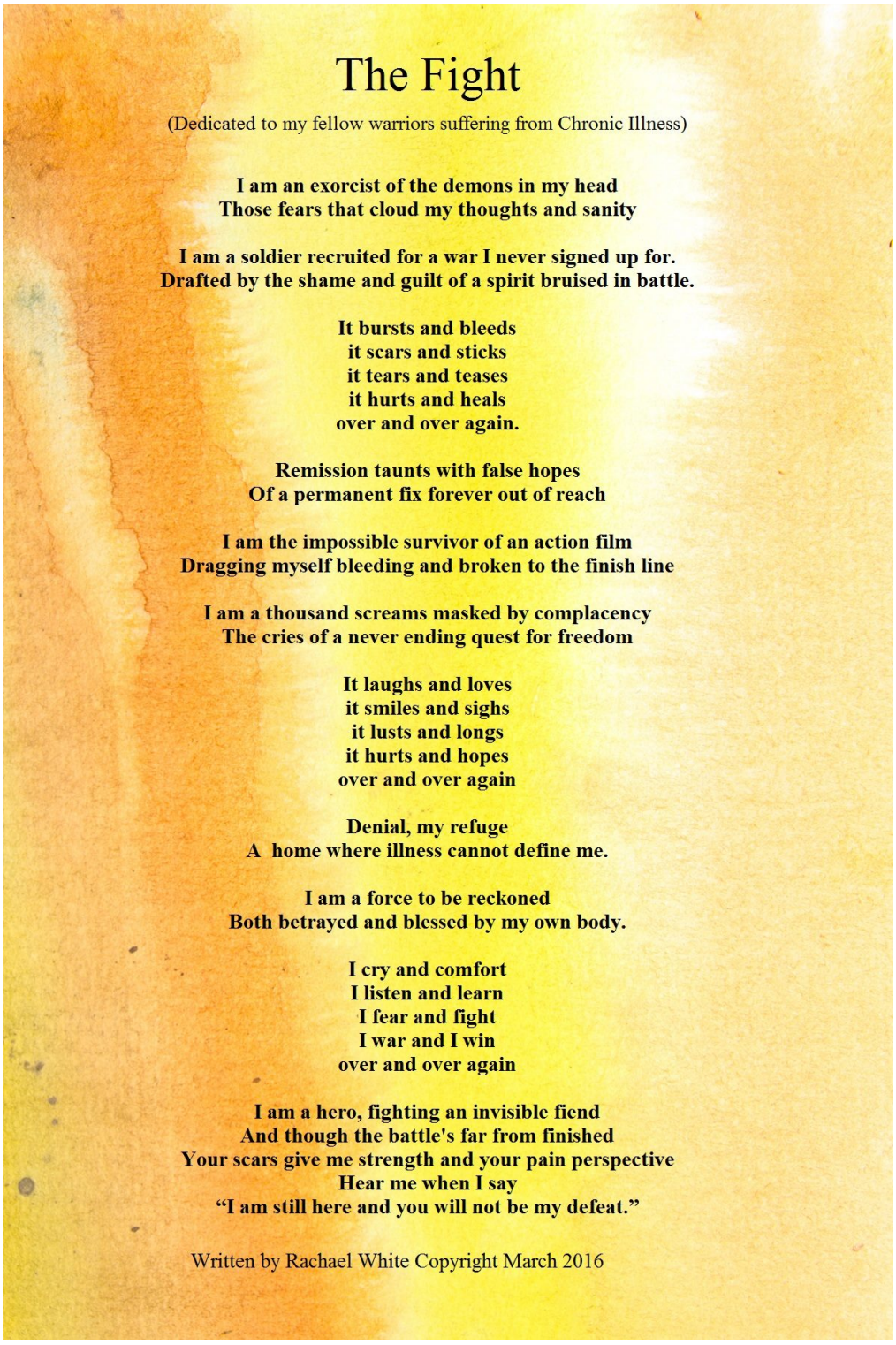
> *Here is a poem I wrote about my own struggle with this disease.*

> *Feel free to share. It could be your friend, mum, sister, that you help. The more we let women know about this disease, the quicker the diagnosis. We will no longer suffer in silence!*-O

Her poem speaks of soldiers recruited involuntarily for the war. Endometriosis warriors are pressured by shame and guilt to join the fight. The recurring engagements result in a spirit that is repeatedly weakened but still unbowed. She employs the vivid imagery of a survivor of an action film: '*Dragging myself bleeding and broken to the finish line'*. She evokes a never-ending fight for freedom from an invisible fiend who she vows will not defeat her.

The fight is not just against endometriosis but also about the issue of delayed diagnosis and ultimately what I am calling the a-diagnostic category. Diagnostic delay has become of vital importance to the endometriosis movement with many women focussing on this as a goal. The recent campaign around Diagnostic Delay by Endometriosis UK, the #Too Long Campaign, has asked women with endometriosis to take photos of themselves and add a sign stating how long it took for them to receive a diagnosis.

> Currently, the average time to diagnose endometriosis is 7 years. This is #TooLong and constitutes an injustice for women and girls across the country. Take part in our #TooLong Donation Campaign: https://www.endometriosis-uk.org/toolong-campaign Accessed April 12, 2016.



The Fight

(Dedicated to my fellow warriors suffering from Chronic Illness)

I am an exorcist of the demons in my head
Those fears that cloud my thoughts and sanity

I am a soldier recruited for a war I never signed up for.
Drafted by the shame and guilt of a spirit bruised in battle.

It bursts and bleeds
it scars and sticks
it tears and teases
it hurts and heals
over and over again.

Remission taunts with false hopes
Of a permanent fix forever out of reach

I am the impossible survivor of an action film
Dragging myself bleeding and broken to the finish line

I am a thousand screams masked by complacency
The cries of a never ending quest for freedom

It laughs and loves
it smiles and sighs
it lusts and longs
it hurts and hopes
over and over again

Denial, my refuge
A home where illness cannot define me.

I am a force to be reckoned
Both betrayed and blessed by my own body.

I cry and comfort
I listen and learn
I fear and fight
I war and I win
over and over again

I am a hero, fighting an invisible fiend
And though the battle's far from finished
Your scars give me strength and your pain perspective
Hear me when I say
"I am still here and you will not be my defeat."

Figure 9.29
The Fight, a poem written by Rachel about her struggle with endometriosis.

The images resulting from the call mainly showed women either hiding their faces or showing their belly, often while lying in hospital after a surgery. Figure 9.30 shows a woman with her face behind a notebook on which is written 12 years #Too Long, #Endometriosis Awareness Week.

Figure 9.30

12 years#too long - #endo awareness week.

Figure 9.31

Panel of several images focussing on the fight for short diagnostic times and for cures.

In contrast, Figure 9.31 shows a collage of images fused together of a woman in a hospital gown with oxygen in her nose, with that same woman holding a sign stating that: '10 years is too long' and asking to find a cure for endometriosis. So the fight becomes not only for short diagnostic times but also for effective treatment and ultimately a cure.

Another main goal of the endometriosis movement is to break the silence, to make sure voices are heard. This remains largely linked to problems of stigma and taboos linked to menstruation. Janet, for example, had spent much time writing to magazines about endometriosis, noting that because endometriosis is not considered life-threatening or a cancer it is not taken seriously. She explained online in her post:

> *I'[ve] had endo since 2006 and Iv had seven laparoscopies and due my 8th one at first I kept silent, then I started to talk to other patients on the ward. Then I got so fed up of this illness being down played that I got louder and louder and know I talk to anyone that will listen, iv written to Take a Break on line and other magazines and coz its not cancer or a life fearing illness even though it ruins millions of women life's, they still won't print it. So I say all us yellow fighters [are] the strongest women I know-To stand up and be counted.....*-O

Stand up and be counted, speak to anyone who will listen; these become the goals, the paradigm under which the movement must function. Voices must be heard despite the opposition, which is still linked to 'a man's world', to the stigma attached to endometriosis. Sandy explained, again online:

> *It is very interesting. Is it still a 'man's world' we live in? Sometimes it seems that way. I personally find that it can be women who shut down when you try speaking about endo. It would be very interesting to know who the editors of those magazines are Emma-Lippylouise Brown, women or men. For the month of March I flooded my FB wall with endo information, both personal and fact, I have never done it before. Now, if I had posted a cute photo of a dog I would have gotten much more response. I think people just don't understand how they are meant to react, the medical professionals (not all) still don't take us seriously. Endo is a very lonely, misunderstood disease, which means we have to yell and scream louder than anyone else.*-O

For her, because endometriosis remains taboo, it is not taken seriously by editors of magazines, doctors or those people on her Facebook page who respond more to cute photos of dogs than to information on endometriosis. Despite this, '*We have to yell and scream louder than anyone else'*-O.

The keynote speaker for the 2016's World Wide EndoMarch, Dr Jhumka Gupta in Washington D.C., USA called endometriosis a silent epidemic caused by social pathologies such as gender inequality and social injustices like being told 'pain is something you must endure' (Gupta 2016). She evoked stigma and ultimately structural violence as causes for the silence around endometriosis. She called for joining together to hold media accountable for misinformation about endometriosis and for women with endometriosis, their families and their doctors to:

> … take ownership of the problem of endometriosis and be an interrupter of its social pathologies. We need you to be an interrupter and speak up when you learn of a teenage girl missing school due to her periods. We need you to speak when you hear people say that endometriosis is not a real disease. We need you to be an interrupter and remind people that suffering can be visible and invisible, so that they too are aware of their blind spots (Gupta 2016).

However, it is not just voices that need to be heard. The ultimate goal is for endometriosis to be recognized as an urgent public health matter so that diagnostic times can be reduced, research on endometriosis can be increased, and adequate access to medical care can be secured.

Figure 9.32 asks 'How many more women and girls will be harmed before endometriosis is recognized as an urgent public health issue?*'* It shows photos of several people all with sticky notes over their mouths, some saying: 'Stop the Silence' in various languages, and others with the word 'Hope'. The woman who posted Figure 9.32 attached her 'quote of the day',

> *In my view, the evidence is incontrovertible; women with endometriosis are being denied adequate medical care. It's the short change of the century that the world simply refuses to acknowledge. So, that's why you will see us marching next year, and the year after that, and the year after that, and the year after that, and the year after that. We are not going away. We demand justice and we will*

march until the end of time if we have to, until our voices are heard and our community's grievances are addressed. –Anonymous -O https://www.facebook.com/photo.php?fbid=10104838766919113&set=gm.437897613073949&type=3&theater Accessed April 22, 2016

Thus, it is not only important to be heard but to receive adequate medical care. Justice now is demanded and grievances are to be addressed. The preceding demands are based on a wish for an augmented voice in the public sphere, but there is also the request for improved clinical care of the condition.

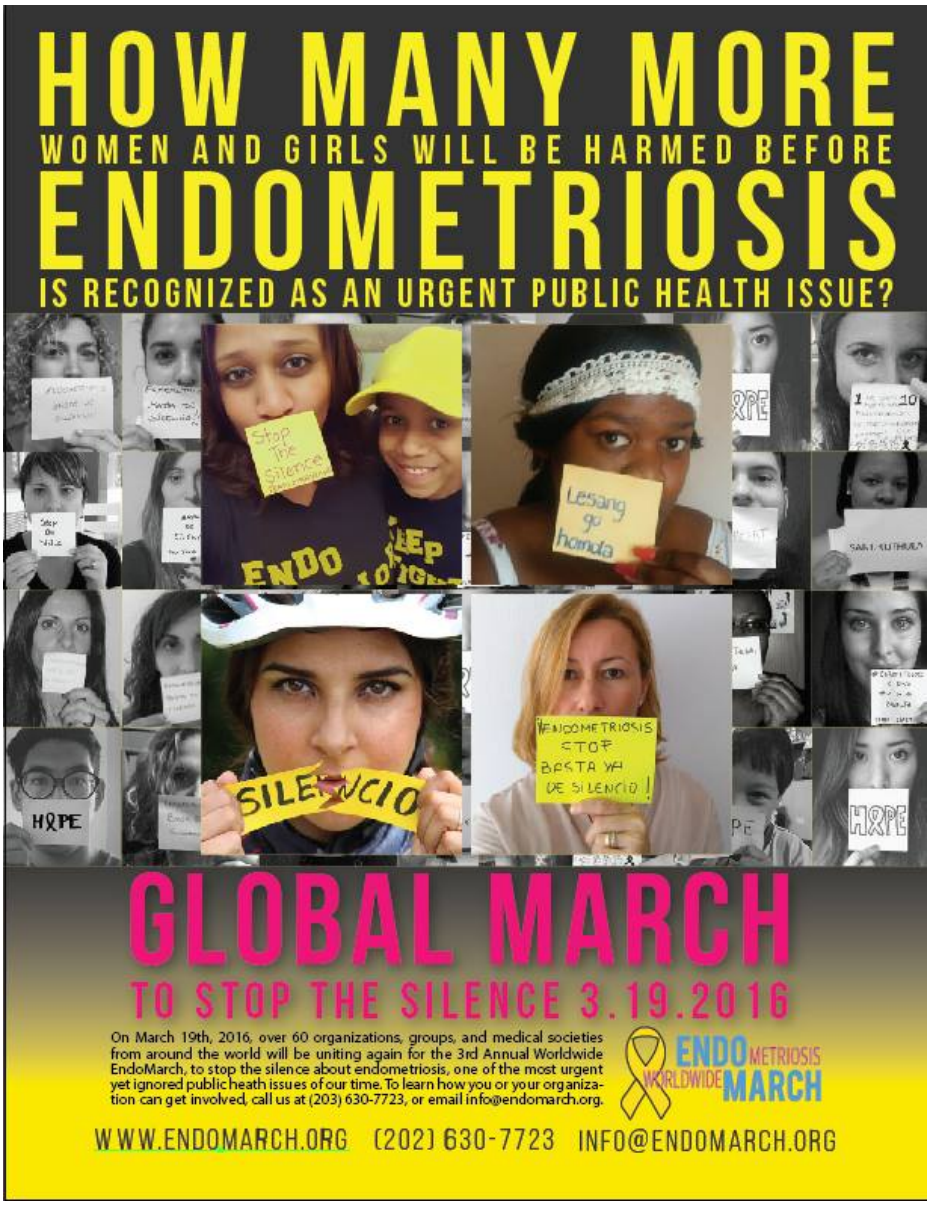


Figure 9.32
Poster advertising the 2016 Endometriosis Worldwide March.

VIII. Conclusion

I have presented an endometriosis movement that effectively has three facets: two externally oriented, the first towards the general public and second towards the medical community, and one internally oriented aspect. The first facet presents itself as feminist and a women's health movement and sees endometriosis as a condition solely of women. This frames the movement as one exclusive to 'women' and thus assumes 'woman' as a fixed category both through the gender binary and through the presentation of the 'woman' with endometriosis as typically Caucasian. This serves to break up the biosocial community and exclude not only those who do not ascribe to the gender binary or do not consider themselves women, but also women of colour. Thus potential multiplicities of endometriosis sometimes tend to be limited, while a simpler model of the disease prioritizes endometriosis as a disease of Caucasian women. This has resulted in a frame-shift where resistance to the idea of endometriosis warriors as women and to the emphasis on Caucasian women has begun to emerge. This parallels previous frame-shifts within both first and second wave feminism with the women's health movement suffering from its use of 'an essentialist approach to "woman" as a fixed category and reference unit for political action and identity' (Kuhlmann 2009: 139). This issue represents an on-going debate in feminist theory (West and Zimmerman 1991, Butler 1990).

The second facet of the endometriosis movement interacts primarily with the medical community. This represents a second frame-shift within the movement and highlights a conflict between Endometriosis UK and the SHE Trust on the use of complementary and alternative medicine and how much biomedical explanations of endometriosis and their associated treatments should be accepted. Thus, Endometriosis UK, in accepting the biomedical notions more readily, also interacts much more with the biomedical community than does the SHE Trust. In doing so, Endometriosis UK takes on more of the vocabulary and rhetoric of biomedicine while still attempting with some difficulty to present the illness narrative as experiential knowledge and therefore of value to the medical community.

The third facet of the endometriosis movement remains an internally oriented one that seeks to provide support by women with endometriosis to women with endometriosis, thus decreasing the likelihood of isolation and creating a 'sisterhood'. This represents a form of biosociality (Rabinow 1996) which links women together on the basis of a common disease and also on certain characteristics of womanhood.

All three facets represent, not internal frame-shifts, but concurrent prongs of a tool used to 'fight a war'. With rhetoric and imagery around 'endometriosis warriors' and 'fighting like a girl', the endometriosis movement ultimately seeks to 'battle' not only endometriosis itself, but also stigma, notions of 'It's all in Your Head' and the associated positioning in the a-diagnostic category, and 'suffering in silence' by listening to and amplifying many voices. The 'war', which continues on all of these fronts while also emphasizing the need to increase funding for research as well as seeking recognition of endometriosis as an urgent public health issue, needs one singular endometriosis or at the appearance of one conjoined, fused disease to address these issues. So while the movement could benefit from broad recognition that endometriosis is a disorder with multiple enactments on the one hand, on the other hand, especially in the context of socio-political advocacy, a more unified and comprehensive view of the disease has certain benefits. For example, in this chapter exploring facets of the war that engages the endometriosis warrior, one can readily see the potential benefits that might flow from unification of those engaged in the social and political struggles on behalf of women with endometriosis.

CONCLUSION

I. Introduction

Endometriosis:

> It is exhausting. It is chronic. It is now your normal. But these things, although real, do not indicate illness to others. They are not seen. They are private. There will be eyebrows raised. Questions. … A lot of questions. People not believing you. Not believing in that deep ache, capable of consuming you. Starting out as a twinge, then a tug, then a throb. Deep. In the center of you. Ebbing out. Growing. Filling up your body. Expanding at the edges. Taking hold of you. They do not believe in that. They do not believe it can really be that bad. It is invisible. It can be felt but it cannot be seen. Not at the dinner table or in the office or at a family gathering or at a birthday party. But your pain is real. Your illness is real. …
>
> This disease can be seen in the operating room. When you are unconscious with a tube in your throat and a needle in the back of your hand. Incisions made in your abdomen. One on the left. One on the right. One inside your belly button. Sometimes more. Air is inserted. Your abdomen expands. Large, distended, bloated and alien-like. Doctors in scrubs, with hair and mouths covered, looking at a screen. They can see it now. Moss-like. Thick. Blue burns like charcoal. Red swollen lesions. A bowel stuck to the abdominal wall. Disease sprinkled throughout the pelvis. Sometimes scattered, sometimes flooded. Enveloping everything. Disease everywhere.
>
> But this cannot be seen on the bus. Not at breakfast tables. Not in lecture halls or at wedding receptions. Not in break rooms. Not in bed alone at night. So you will explain this. You will spend a lot of time explaining. Defining. Justifying. You will want to be heard. You will want to be believed. You will pursue that feeling you had in the hospital bed the first time. That first time you heard it. Disease. Illness. (Millar 2017)

In switching from descriptions of twinges, throbs, tugs, chronicity, and exhaustion to visualised lesions, bowel stuck to abdominal walls, and to descriptions of a woman lying unconscious in the operating theatre, Millar eloquently describes some of the multiple enactments of endometriosis. Yet she also drives home the emotional effect of what I have called the a-diagnostic category. Before diagnosis 'no one believes you', but after diagnosis you are still left to define, to justify, and to pursue that feeling when the endometriosis label was first uttered – when you were believed. She shows us how

fleeting escape from the a-diagnostic category can really be and how much work is required by women to truly gain and keep the endometriosis label.

II. Review

In this thesis, I have examined multiplicities of endometriosis and the interplay with what I have called the a-diagnostic category through an ethnographic study that draws on fieldwork conducted primarily in the UK from June 2013 to August 2014. The study took place in several settings that included a gynaecology clinic, a medical conference on endometriosis, the internet, various endometriosis support group meetings, and awareness campaign events. To my knowledge, the work represents the first ethnographic study on endometriosis that involves both women with endometriosis and associated medical professionals. Its multiple methods include a specific focus on visual representations of endometriosis posted on online media, a relatively new method in the field of endometriosis study.

I began the thesis by putting forward a theoretical framework, one where I focussed on notions of multiplicity of disease (Mol 2002) and disciplinary power (Foucault 2004), while laying out a new concept that I call 'the a-diagnostic category'. I then turned to the methodology and ethics involved in this research. In Chapter 3, I examined present-day enactments of endometriosis through an historical lens, specifically focussing on how past understandings of menstruation as 'normally painful' limit what is considered endometriosis in the present day. This has long-standing, often negative effects on women's ability to access the diagnosis of endometriosis and results in many women's positioning in the a-diagnostic category.

In Chapter 4, I examined in some detail what I am calling the a-diagnostic category. I outlined a definition which entails women's recognising that something is 'wrong' with them. However they search repeatedly and without success for a diagnosis that could lead to future treatment. In Chapter 5, I looked at enactments of endometriosis in the clinic and the ways in which gynaecologists limit who can access the endometriosis label through lay-professional epidemiology. In Chapter 6, I looked at what I have called 'control strategy' usage in the clinic. While women with endometriosis were

using control strategies as a way out of the a-diagnostic category, gynaecologists utilised them to subvert a medical system pressuring them to cure every patient. Some women were pushed out of the medical system and back into the a-diagnostic category despite having had a previous diagnosis of endometriosis.

In Chapter 7, I described how three forms of stigma directly related to endometriosis (stigma of menstruation, stigma of sex, and stigma of childlessness) shaped modes of disciplinary power in a clinic setting and ultimately limited women's access to the endometriosis label, leaving them stuck in the a-diagnostic category. These types of enactments are found inside and outside the biomedical clinic. In Chapter 8, I contemplated how women 'talk bodies' (Mol 2002) and related enactments of endometriosis outside of biomedicine and highlighted the potential clashes of such enactments with biomedical understandings of endometriosis. For example, visual representations of endometriosis belied a sharp contrast between the emotional components of pain and the microscopic images that doctors may recognize as endometriosis. On the other hand, women viewed endometriosis as having a psychological component. Biomedical understandings of endometriosis often kept such links to mental health both separate from the disease and part of the a-diagnostic category. Finally, in Chapter 9, I examined the endometriosis movement in detail. The struggle to gain a diagnosis, one singular label, and staying out of the a-diagnostic category remain at the forefront of the activism.

While each chapter looked at specific multiplicities of endometriosis, the ways in which they all come together are not simply through use of the same name. Part of the unifying process comes from the struggle to achieve that one singular label and the consistent push to keep it, in the face of constant threats to take it away. Enactments of endometriosis come with that added question of their 'realness', their authenticity. A woman with endometriosis 'will spend a lot of time explaining, defining, justifying' (Millar 2017). Such activity constitutes a form of enacting. Ironically, the a-diagnostic category creates another enactment of endometriosis.

III. Contribution to Medical Anthropology

This thesis tells us about endometriosis. It tells us about enactments of disease. Here women 'talk bodies'. They tell of their 'failed bodies', of the impact of the disease on relationships. They not only talk of pain, but paint it, and visually represent it. They have their own pain scales. They use a different form of communication to talk about pain, and in so doing expand on notions of the anatomy and physiology of the body. Studying these disease ontologies allows for a broader understanding of endometriosis as a disease beyond biomedical definitions or visualised pathology, knowledge that can be taken into the clinic room. Such enactments bear witness to a patient's life, to disease outside the hospital but also within it. Examining enactments of disease allows us to link together disease entities into a whole. It gives us a picture of how the multiplicities of disease come together not only in endometriosis but potentially in other chronic illnesses.

Women with endometriosis talk of stigma which limits their ability to access the label of endometriosis and any associated care. But women with endometriosis also speak of being 'fobbed off', of a struggle to be taken seriously, and ultimately an emotional journey to gain access to care. They talk about this in support group meetings, online, and in interviews. They teach each other how to be believed, how to go to the doctor to get care. Women spend years looking for a diagnosis and years doubting themselves. All of this impacts on enactments of disease in the clinic. It means women lack trust in their doctors, or are prepared for a fight in the clinic room. This impacts on disease enactments outside the clinic as well. It tells us how endometriosis evolves in a woman's life.

Only through different forms of ethnographic methodology was I able to get such rich data. My use of visual representations of endometriosis posted online by women is a novel approach in medical anthropology. In addition, my examination of the endometriosis movement covers both online and in-person elements of the movement, and is thus a novel description of its kind. Through these methods, I have been able to describe a new ethnographic category: the a-diagnostic category. I have observed a

hidden phase in the evolution of the disease that people rarely mentioned before. I outline how the enactments of disease unfold over time. Women often have symptoms but no diagnosis for years, if not decades.

The concept of the a-diagnostic category is a distinctive contribution to the field of medical anthropology. It is an ethnographic category through which we can make sense of the relationship between medical knowledge and actual practices within medicine. There is often a gap in biomedicine between knowing and doing, where doctoring is tentative guess-work and requires tinkering (Mol 2008, Street 2011, Struhkamp et al 2009). Doctoring also requires a collaborative relationship between doctor and patient, one that is challenged by the a-diagnostic category because of the tension produced by the discontent of both parties. The a-diagnostic category represents a form of exclusion from the possibilities of shared doctoring practices based on tinkering and collaboration. It is not a category clinicians officially recognize or even acknowledge using. Despite this, it remains common in the practice of endometriosis care, often leaving patients feeling unbelieved and distrustful of their medical professionals. This thesis begins therefore to highlight forms of exclusion that take place in the gaps between medical knowledge and medical practice and the ways that diagnostic labels act to bridge this gap. This allows us to begin our understanding of how these forms of exclusion work.

While highlighting the multiplicities of endometriosis and the a-diagnostic category is important, acknowledging these enactments is not something to be done as an isolated academic exercise. Mol (2002) emphasizes that point. In the end, we have to ask what we should make of these multiplicities and movement into the a-diagnostic category. The delay in diagnosis of endometriosis is well known, with an average of 7-10 years across the world. This delay causes women to struggle with continued pain, in isolation, and with feelings that they are 'weak' compared to other women. I hope my work helps contextualize reasons for this delay, including the effect of historical understandings of menstruation and the uterus on present-day views of endometriosis and the difficult differentiation of dysmenorrhoea, 'normal' menstruation and endometriosis. Stigma relating to menstruation, sexual intercourse, and childlessness

contribute to women's prolonged struggle to obtain a diagnosis. This struggle is complicated by further multiplicities of endometriosis, with clinicians' possessing their own 'lay-professional epidemiology' of endometriosis which differs from clinical guidelines and medical textbooks on the disease. Examples of the lay-professional epidemiology are that teenagers and post-menopausal women are not thought to be potential endometriosis patients. Furthermore, the defining of endometriosis as a disease of educated, white, heterosexual women excludes many sufferers with the condition. All of this limits practical access to diagnosis, which in turn limits access to care. It also aids our understanding of the endometriosis movement and why so many women with endometriosis report being told 'It's all in your head' and experience difficulties in their interactions with medical professionals.

IV. Escaping the A-Diagnostic Category

> A 36-year-old woman presents to the emergency department because of pain. She has visited her primary care physician multiple times in the past several months for various pain-related complaints. On each occasion, no physical or laboratory findings were found to explain her symptoms. The patient has no worker's compensation cases open. She is quick to suggest treatment options and listens intently whenever any medical professionals are in the room.
>
> Which one of the following characterizes her unexplained physical symptoms?
>
> A. Somatization disorder
> B. Conversion disorder
> C. Hypochondriasis
> D. Malingering
> E. Munchausen syndrome
> (Twitter 2018)

The above is a practice test question on a national examination that medical students in the United States must pass in order to graduate from medical school. The question describes a young woman who goes to Accident and Emergency (the emergency department) because of pain. She has repeatedly visited her GP with similar complaints, but physical examination and laboratory tests did not show any obvious

reason for her pain. The test question then goes on to suggest a differential diagnosis for the above presentation. All five causes fall in the realm of psychiatry, with none linked to potential physical or organic causes of pain, such as endometriosis.

A woman comes in repeatedly to see the doctor with complaints of pain. At some point the pain is so bad she feels the need to go to the hospital to the Accident and Emergency department where likely she has had to wait anywhere between 2 and 6 hours. Because her laboratory findings are normal and there are no overt physical symptoms, the explanation offered falls in the psychological arena. This test question replicates the trajectory experienced by many of the women in my study.

A central question remains. How do we get patients out of the a-diagnostic category so that they can access medical care and treatment? We should remember that endometriosis is a heart-breaking, severely painful disease and one in which as many as 50% of women felt their GP did not take them seriously when they first presented with symptoms and 65% were initially diagnosed with another condition (Overton 2010). There is no easy answer to this problem. However, I suggest that we start with increasing awareness of stigma and of misleading information about the very limiting notions of endometriosis as a disease of white, career women. In a March 2018 Facebook live event discussing the 2017 NICE guidelines of endometriosis, a gynaecologist stated that teenagers are not yet acclimated to how painful menstruation is. How can a thirteen year old who has such levels of pain that she cannot attend school expect to access care? Doctors must be aware that a disease exists if they are to diagnose it. So, we should start by teaching medical professionals, the general public, and researchers that endometriosis may affect women of all ages, including women of colour and non-heteronormative, non-binary individuals too.

Women online are still questioning why there is so little awareness of endometriosis not only among lay people but also among specialist and non-specialist physicians. One of the leaders of the Worldwide Endometriosis March, Dr. Camran Nezhat, has stated that all doctors need to know the basics about endometriosis.

> Too many new medical school graduates still do not know the basics about endometriosis. Since endometriosis is a common, whole-body chronic disease, which can affect many parts of the body, all disciplines of medicine must be taught to recognize potential symptoms & refer patients to a specialist when endometriosis is suspected. (Nezhat 2018)

Of course, a subsidiary problem may have to do with the basics of endometriosis. I have highlighted some elements that are among the 'basics' of endometriosis. I suggest we should be teaching about the multiplicities of chronic diseases like endometriosis and how multiple enactments take place. Such knowledge should lead to a better understanding of the disease, with shorter times to diagnosis and avoidance of the a-diagnostic category.

We should acknowledge that as medical professionals, we dismiss patients sometimes and they end up in the a-diagnostic category. The a-diagnostic category must be tackled. I do not intend to place the problem solely at the feet of medical professionals. It is not solely their responsibility. GPs are not entirely at fault for their role as gatekeepers in the medical system that is the NHS; nor are gynaecologists who also are expected to limit the number of patients they keep on their list or the number of surgeries they perform.

Gatekeeping is introduced because it is part of an organised health system. It allows for reduced cost. If every patient could go directly to a specialist, it would make the whole system prohibitively expensive, an issue that is commonly discussed in the British press about the NHS. For example, if a child falls and cuts his forehead the parents might want a cosmetic surgeon to treat him. But of course, it is cheaper to see a GP first (or perhaps a paediatrician in the US) with the expectation that the GP be able to triage appropriately and determine whether the child needs to be seen by neurology for any head trauma and be able to stitch a fairly straight-forward cut. Instead of sending the child to the Accident and Emergency (Emergency Medicine) department, the GP will likely send the child home with directions to the parent to watch the child during the next few days and return if the child's condition worsens. So while this system

diminishes choice for the patient, it still allows for care (Mol 2008). The system fails us when it is not clear that the patient should be sent on to see a specialist, or have further tests to determine whether surgery may be necessary. The a-diagnostic category is an example of where the system fails the patient. In this context, women are effectively displaced from the medical system (at least for that particular complaint) into a holding pattern that struggles to provide care. I am suggesting that improved understanding of the intimate mechanisms of endometriosis should facilitate women's exit from the a-diagnostic category.

There are of course other complicating elements. There are no laboratory tests that can diagnose endometriosis. Blood biomarkers such as CA125, CA19-9, interleukins 6,8, and 10 and tumour necrosis factor have all been studied in endometriosis, but none has been validated as a non-invasive diagnostic test (Oliveira et al 2017). At the moment, we are still struggling to confirm the diagnosis of endometriosis by a method that is not too dangerous or invasive. Currently, diagnosis is by laparoscopy (keyhole) surgery, by visualisation of tissue. This is a problem. Diagnosis through surgery means risk of infection, of blood loss, and sometimes of death. It means recovery time (6-8 weeks usually); it means time off work or school. Laparoscopies are expensive. This money must come from somewhere: either through the health system (as is the case of the NHS) or through personal funds.

Not only do women struggle to obtain the surgical diagnosis, they also are dependent on how trained their doctors are. Technical competence of the medical professional is important in diagnosing endometriosis. Thus, biomedical research into biomarkers and genetic profiles remain primordial in finding less invasive ways of diagnosing endometriosis. This is even more important as endometriosis has recently been linked to higher risk of coronary heart disease (Mu et al 2016). In addition, 'some cancers (ovarian cancer and non-Hogdkin lymphoma) are slightly more common in women with endometriosis' (Dunselman et al 2014).

V. Future Directions

Delays in successful treatment that women with endometriosis report affect both their physical and mental health. Thus, improving the understanding of the barriers to treatment of endometriosis would be particularly beneficial. This includes studying how research directions for endometriosis are decided, how results are interpreted, and how treatment options are prioritized.

Further research is also needed around GPs and their understandings of endometriosis and how they utilize and provide the endometriosis label. While I did originally intend to include this in my PhD, I was unable to recruit participants to this part of my study. This remains of particular relevance, as in the UK GPs are gatekeepers for access to gynaecologists and potential treatment of endometriosis. In addition, the characterization of endometriosis as a disease of white, educated, and heterosexual women is problematic and misleading. This claim ignores my findings in Chapter 5 that women with lower socioeconomic backgrounds struggled more to receive a diagnosis of endometriosis and my findings in Chapter 9 where questions have arisen over the assumption that endometriosis affects only 'women' and over the potential exclusion of women of colour. Future research should expand its scope to consider endometriosis in women of colour and others who consider themselves to be non-binary or non-heteronormative endometriosis warriors.

Future research about healthcare professionals' feelings of powerlessness in the endometriosis context is warranted. This could allow a more detailed understanding of why patients find themselves often excluded from a gynaecology clinic and transitioned into the a-diagnostic category, making it difficult to access care. Since women with endometriosis are often sent to the chronic pain management clinic as a way of excluding these patients from the gynaecology clinic (a reaction to doctor's feeling powerless in the gynaecology clinic), it would be important to examine enactments of endometriosis in a chronic pain management clinic setting. Examining in depth the ways in which medical professionals in a chronic pain management clinic setting see their role might help to elucidate why they do not experience powerlessness in the same

way as their gynaecologist counterparts. Specifically focussing on notions of how chronic pain clinic healthcare professionals reconceptualise endometriosis complaints into chronic pain complaints may also allow for greater understanding of enactments of disease on feelings of powerlessness in the clinic.

VI. Applying the A-Diagnostic Category to Other Conditions

The US national exam question caused a strong enough backlash that the 'Medscape' website where it was originally posted on July 25, 2018 took it down a day later. With the recent uproar on Twitter, it is clear that acknowledging the presence of the a-diagnostic category is of the utmost importance, and not just to endometriosis scholarship. The complaints centred on women's health and women's voices being ignored about their own bodies. If the notion that pain in women is to be associated with various mental health categories, some of which are associated with 'fake physical symptoms', and is being taught throughout the United States and expected to be learned by all medical students, then we have a long way to go. I therefore suggest that doctors and medical students begin to be sensitized to this issue.

In May 2018, the BBC published an article called, 'Everybody was telling me there was nothing wrong', in which they highlighted several lines in bold. The first sentence was:

> Women are more likely to wait longer for a health diagnosis and to be told it's 'all in their heads' (Dusenbery 2018).

You might assume this was about endometriosis. Actually, the article was about brain tumours in the UK and how women struggle to obtain a diagnosis, such that treatment is delayed. Women must work for the correct diagnosis in a myriad of conditions, including heart disease, where women have a 50% higher chance of an initial incorrect diagnosis than men; and stroke, where women are 30% more likely than men to be sent home from the hospital without a diagnosis (WebMD 2018). It takes an average of between 4.6 years

and 5 doctors for one to receive a diagnosis of autoimmune diseases (including multiple sclerosis, lupus, rheumatoid arthritis, and thyroid disorders), conditions in which 75% of patients are women (WebMD 2018).

I show these examples to point out that the a-diagnostic category has far-reaching and potentially negative consequences. Movement into the a-diagnostic category can be lethal with 'diagnostic errors caus[ing] 40,000-80,000 deaths in the US alone' (Dusenbery 2018). Women are less likely to survive acute myocardial infarctions (heart attacks) than men and their possibility of survival decreases when being treated by male physicians, an effect that decreases as male doctors work with female colleagues or treat more female patients (Greenwood et al 2018). This suggests that the effect of the a-diagnostic category can be mitigated if we acknowledge it.

In the interplay between the a-diagnostic category and multiplicities of disease, we can see the ways in which social determinants limit access to diagnosis and treatment. In endometriosis, this manifests itself through understandings of 'normal' menstruation as painful by definition and with women's pain being interpreted as 'psychological' in origin. I suspect also that movement into the a-diagnostic category will be dependent on socioeconomic factors and race. It has already been documented that 'beliefs and expectations regarding minority patients' may affect the length of doctor-delays relating both to diagnosis and optimal pain treatment (Anderson 2009: 1194, Nguyen et al 2005). Patients 'with better bargaining power, primarily those with higher education and health-related employment, [are] more likely to question doctors' dismissal of their symptoms' (Markovic 2008: 363 citing Peters et al., 1998). This implies that those patients in lower socioeconomic brackets may be more likely to accept a doctor's dismissal of their symptoms, further delaying diagnosis and extending time in the a-diagnostic category.

I give these examples, as this is what I know. There may be other conditions where the a-diagnostic category is relevant. I hope that others may see its usefulness and use the

concept to provide better care to the patients involved, because after all that is the goal of this scholarly observation and reflection.

VII. Final Thoughts

Endometriosis remains a condition affecting one in 10 women or approximately 176 million women worldwide. Despite its strong impact on women's physical and mental health, this epidemic remains largely hidden because of the stigmatizing nature of the condition. To the one in 10, I hope that this thesis will help bring endometriosis to the forefront, contribute to improvements in the health care of the women affected, and help decrease the time to diagnosis and treatment.

Figure 10.1

Stay strong, keep your head up to the sky, and sparkle on in spite of it all.

#endostrong #endowarrior #positivevibes

Appendix A: Patient Consent Form

Centre Number:
Study Number:
Participant Identification Number for this trial:

CONSENT FORM

Title of Project: Examining Doctors' and Patients' Narratives in Endometriosis

Name of Researcher: Dr. Veronique Griffith

Please initial box

1. I confirm that I have read and understand the information sheet dated June 29, 2012 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of my medical notes and data collected during the study,may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I consent to the collection of audio recordings and the use of this information in research. ☐

5. I consent to participate in this study. ☐

Name of Patient Date Signature

Name of Person taking consent Date Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes.

Appendix B: Doctor Consent Form

Centre Number:
Study Number:
Participant Identification Number for this trial:

CONSENT FORM

Title of Project: Examining Doctors' and Patients' Narratives in Endometriosis

Name of Researcher: Dr. Veronique Griffith

Please initial box

6. I confirm that I have read and understand the information sheet dated June 29, 2012 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

7. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without affecting my status as an employee of the NHS or legal rights being affected. ☐

8. I understand that data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. ☐

9. I consent to the collection of audio recordings and the use of this information in research. ☐

10. I consent to participate in this study. ☐

Name of Participant Date Signature

Name of Person taking consent Date Signature

When completed, 1 for participant; 1 for researcher site file.

Appendix C: Interview Questions for Patients

1. Please describe your endometriosis trajectory ie when you first had symptoms and when you were first diagnosed.
2. How has your life been affected by endometriosis?
3. Please describe your experience with doctors.
4. In what ways do you feel treatment for endometriosis could be improved?
5. What would you have liked to have been told or known about endometriosis at the beginning of the journey?
6. How has endometriosis affected your relationships with your family members, friends, co-workers?
7. How many days of pain have you experienced in the last month?
8. What level was the pain on those days (Pain scale from 0 to 10, 0 representing no pain at all and 10 being the worst pain you can imagine)?
9. How did these affect your ability to function?
10. Have there been any days in the last month when you felt down? What do you think contributed to this feeling?
11. How in control of your endometriosis do you feel?

Appendix D:

Interview Questions for Obstetrician-Gynaecologists and Specialist Gynaecologists

1. Describe your experience with patients with endometriosis or suspected endometriosis.
2. What would be your management of a patient with endometriosis or suspected endometriosis?
3. What sort of interventions are there for this patient group?
4. What do perceive to be issues specific to endometriosis?
5. Why do think it can take such long time for diagnosis of endometriosis?
6. Do you feel that giving a patient a diagnosis of endometriosis helps?
7. Have you had any patients that you would classify as 'problem' patients? If so, what do you think contributed to this feeling? Do you think you could have done anything differently?
8. How much do you think psychosocial aspects contribute to endometriosis?
9. What do you think other obstetrician-gynaecologists need to be mindful of when treating suspected endometriosis patients?
10. What do you think GPs need to be mindful of when treating suspected endometriosis patients?

Appendix E:

Interview Questions for Pain Clinic Medical Professionals and Pain Consultants

1. Describe your experience with patients with endometriosis or suspected endometriosis.
2. What would be your management of a patient with endometriosis or suspected endometriosis?
3. What sort of interventions are there for this patient group?
4. What do perceive to be issues specific to endometriosis?
5. Why do think it can take such long time for diagnosis of endometriosis?
6. Do you feel that giving a patient a diagnosis of endometriosis helps?
7. Have you had any patients that you would classify as 'problem' patients? If so, what do you think contributed to this feeling? Do you think you could have done anything differently?
8. How much do you think psychosocial aspects contribute to endometriosis?
9. What do you think gynaecologists need to be mindful of when treating suspected endometriosis patients?
10. What do you think GPs need to be mindful of when treating suspected endometriosis patients?

Appendix F: Participant Information Sheet for Patients

Version 2: June 29, 2012

Examining Doctors' and Patients' Narratives Surrounding Endometriosis

Protocol Reference # 12/EE/0278

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

What is the purpose of the study?

Because of its lack of cure and chronicity, the endometriosis illness experience extends well beyond physical symptoms and therefore has a significant impact on the quality of life of patients with endometriosis (Griffith, 2009). The goal of this study is to deepen our understanding of the doctor and patient narratives surrounding endometriosis, to compare these narratives, and to elucidate how they each effect the nature of the doctor-patient relationship in conditions of diagnosed endometriosis and non- diagnosed chronic pelvic pain. If we can identify the differing visions of clinicians and patients, we hope to pinpoint the reasons behind the challenges in the doctor-endometriosis patient interaction. This information could lead to the identification of tools clinicians could use to increase patient satisfaction. This could help decrease potential delay in seeking care in instances of increased pain, improve access to care, and enhance clinical outcomes.

Why have I been invited?

You have been invited to take part in this research because you are either a patient, GP or specialist gynaecologist or obstetrician-gynaecologist who can share his or her experience of endometriosis.

Do I have to take part?

It is up to you to decide. I will describe the study and go through this information sheet, which we will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

As a patient enrolled in this study, you will be interviewed at your convenience for approximately an hour. The interview will seek to develop a narrative of your journey through the medical system. I will seek to ascertain your view on what distinguishes a positive doctor-patient interaction from a negative one.

In addition, you will be asked questions to determine your quality of life. The interview session will be audio-recorded. Your medical records (both GP and gynaecologist) will also be accessed to allow for a comparison of your story with your doctor's narrative.

Expenses and payments

As a student, I am unable to offer you any money for your participation in this study. However, I do very much appreciate your time and effort.

What are the possible disadvantages and risks of taking part?

It is possible that discussing your experience with endometriosis may make you upset. If you are upset about anything we have discussed and wish to discuss these issues further please contact either your GP, your local endometriosis support group, Samaritans, local support groups, local free/low cost counselling, or PALS. If you need any help with finding the contacts needed please let me know.

What are the possible benefits of taking part?

The study is expected to provide important information on doctors' and patients' narratives on endometriosis. This information could lead to the identification of tools

clinicians could use to increase patient satisfaction. This could help decrease potential delay in seeking care in instances of increased pain, improve access to care, and enhance clinical outcomes.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (**07503556455**). If you remain unhappy and wish to complain formally, please contact the Patient Relations Department – **0191 223 1382**. Detailed information can be found at: http://www.newcastle-hospitals.org.uk/patient- guides/have-say_formal-complaints.aspx.

Will my taking part in the study be kept confidential?

Yes, your anonymity will be maintained throughout with you being only referred to by a designated number and the audio-recording only listened to by the researcher. The recordings will be kept in a locked box and the computer used for producing transcripts and for replaying the recordings will be password protected and any information encrypted. Any print-outs will be kept in a locked box and shredded when no longer needed. Recordings and print-outs will only be kept until the researcher is awarded her PhD as the data will be used in her PhD.

What will happen to the results of the research study?

The results of this research study will form a PhD thesis. In addition, the results may be used for publication in academic journals. All results will be kept confidential within the thesis and in any publications. The results will be made accessible to participants through the Durham University website.

Who is organising and funding the research?

This study is part of a PhD project in the Department of Anthropology, Durham University.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Proportionate Review Sub-Committee of the NRES Committee East of England-Norfolk. In addition, this study has been reviewed by the Ethics Committee in the Department of Anthropology, Durham University.

Further information and contact details

Thank you very much for participating in this study. You will be given a copy of this information sheet and a signed consent form to keep for your records. Please let me know if you have any questions or comments. I'd be more than happy to discuss them with you. Please feel free to contact me at the address or email provided below.

Sincerely,

Véronique Griffith, MD PhD Candidate, Department of Anthropology Durham University

Contact Information: v.a.s.griffith@durham.ac.uk St. Mary's College Elvet Hill Road Durham, Durham DH1 3LR Phone: 07503556455

Appendix G: Participant Information Sheet for Obstetrician Gynaecologists

Version 2: June 29, 2012

Examining Doctors' and Patients' Narratives Surrounding Endometriosis
Protocol Reference # 12/EE/0278

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

What is the purpose of the study?
Because of its lack of cure and chronicity, the endometriosis illness experience extends well beyond physical symptoms and therefore has a significant impact on the quality of life of patients with endometriosis (Griffith, 2009). The goal of this study is to deepen our understanding of the doctor and patient narratives surrounding endometriosis, to compare these narratives, and to elucidate how they each effect the nature of the doctor-patient relationship in conditions of diagnosed endometriosis and non-diagnosed chronic pelvic pain. If we can identify the differing visions of clinicians and patients, we hope to pinpoint the reasons behind the challenges in the doctor-endometriosis patient interaction. This information could lead to the identification of tools clinicians could use to increase patient satisfaction. This could help decrease potential delay in seeking care in instances of increased pain, improve access to care, and enhance clinical outcomes.

Why have I been invited?
You have been invited to take part in this research because you are either a patient, GP or specialist gynaecologist or obstetrician-gynaecologist who can share his or her experience of endometriosis.

Do I have to take part?
It is up to you to decide. I will describe the study and go through this information sheet, which we will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?
As an obstetrician-gynaecologist enrolled in this study, you will participate in an interview regarding past experiences with endometriosis patients or patients who have

presented with chronic pelvic pain. With your permission, this session will be audio-recorded.

Expenses and payments
As a student, I am unable to offer you any money for your participation in this study. However, I do very much appreciate your time and effort.

What are the possible disadvantages and risks of taking part?
It is possible that discussing your experience with endometriosis may make you upset.

What are the possible benefits of taking part?
The study is expected to provide important information on doctors' and patients' narratives on endometriosis. This information could lead to the identification of tools clinicians could use to increase patient satisfaction. This could help decrease potential delay in seeking care in instances of increased pain, improve access to care, and enhance clinical outcomes.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (**07503556455**).

Will my taking part in the study be kept confidential?
Yes, your anonymity will be maintained throughout with you being only referred to by a designated number and the audio-recording only listened to by the researcher. The recordings will be kept in a locked box and the computer used for producing transcripts and for replaying the recordings will be password protected and any information encrypted. Any print-outs will be kept in a locked box and shredded when no longer needed. Recordings and print-outs will be destroyed after the researcher has been awarded her PhD.

What will happen to the results of the research study?
The results of this research study will form a PhD thesis. In addition, the results may be used for publication in academic journals. All results will be kept confidential within the thesis and in any publications. The results will be made accessible to participants through the Durham University website.

Who is organising and funding the research?
This study is part of a PhD project in the Department of Anthropology, Durham University.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Proportionate Review Sub-Committee of the NRES Committee East of England-Norfolk. In addition, this study has been reviewed by the Ethics Committee in the Department of Anthropology, Durham University.

Further information and contact details
Thank you very much for participating in this study. You will be given a copy of this information sheet and a signed consent form to keep for your records. Please let me know if you have any questions or comments. I'd be more than happy to discuss them with you. Please feel free to contact me at the address or email provided below.

Sincerely,

Dr. Véronique Griffith, MD
PhD Candidate, Department of Anthropology
Durham University

Contact Information:
v.a.s.griffith@durham.ac.uk
St. Mary's College
Elvet Hill Road
Durham, Durham DH1 3LR
Phone: 07503556455

Appendix H: Participant Information Sheet for Health Professionals

Version 2: June 29, 2012

Examining Doctors' and Patients' Narratives Surrounding Endometriosis
Protocol Reference # 12/EE/0278

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

What is the purpose of the study?

Because of its lack of cure and chronicity, the endometriosis illness experience extends well beyond physical symptoms and therefore has a significant impact on the quality of life of patients with endometriosis (Griffith, 2009). The goal of this study is to deepen our understanding of the doctor and patient narratives surrounding endometriosis, to compare these narratives, and to elucidate how they each effect the nature of the doctor-patient relationship in conditions of diagnosed endometriosis and non-diagnosed chronic pelvic pain. If we can identify the differing visions of clinicians and patients, we hope to pinpoint the reasons behind the challenges in the doctor-endometriosis patient interaction. This information could lead to the identification of tools clinicians could use to increase patient satisfaction. This could help decrease potential delay in seeking care in instances of increased pain, improve access to care, and enhance clinical outcomes.

Why have I been invited?

You have been invited to take part in this research because you are either a patient, GP, chronic pain consultant, health professional, specialist gynaecologist or obstetrician-gynaecologist who can share his or her experience of endometriosis.

Do I have to take part?

It is up to you to decide. I will describe the study and go through this information sheet, which we will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?
As a health care professional enrolled in this study, you will participate in an interview regarding past experiences with endometriosis patients or patients who have presented with chronic pelvic pain. With your permission, this session will be audio-recorded.

Expenses and payments
As a student, I am unable to offer you any money for your participation in this study. However, I do very much appreciate your time and effort.

What are the possible disadvantages and risks of taking part?
It is possible that discussing your experience with endometriosis may make you upset.

What are the possible benefits of taking part?
The study is expected to provide important information on doctors' and patients' narratives on endometriosis. This information could lead to the identification of tools clinicians could use to increase patient satisfaction. This could help decrease potential delay in seeking care in instances of increased pain, improve access to care, and enhance clinical outcomes.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (**07503556455**).

Will my taking part in the study be kept confidential?
Yes, your anonymity will be maintained throughout with you being only referred to by a designated number and the audio-recording only listened to by the researcher. The recordings will be kept in a locked box and the computer used for producing transcripts and for replaying the recordings will be password protected and any information encrypted. Any print-outs will be kept in a locked box and shredded when no longer needed. Recordings and print-outs will be destroyed after the researcher has been awarded her PhD.

What will happen to the results of the research study?
The results of this research study will form a PhD thesis. In addition, the results may be used for publication in academic journals. All results will be kept confidential within the thesis and in any publications. The results will be made accessible to participants through the Durham University website.

Who is organising and funding the research?
This study is part of a PhD project in the Department of Anthropology, Durham University.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Proportionate Review Sub-Committee of the NRES Committee East of England-Norfolk. In addition, this study has been reviewed by the Ethics Committee in the Department of Anthropology, Durham University.

Further information and contact details

Thank you very much for participating in this study. You will be given a copy of this information sheet and a signed consent form to keep for your records. Please let me know if you have any questions or comments. I'd be more than happy to discuss them with you. Please feel free to contact me at the address or email provided below.

Sincerely,

Dr. Véronique Griffith, MD
PhD Candidate, Department of Anthropology
Durham University

Contact Information:
v.a.s.griffith@durham.ac.uk
St. Mary's College
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Appendix I: Participant Information Sheet for Chronic Pain Consultants

Version 2: June 29, 2012

Examining Doctors' and Patients' Narratives Surrounding Endometriosis
Protocol Reference # 12/EE/0278

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

What is the purpose of the study?
Because of its lack of cure and chronicity, the endometriosis illness experience extends well beyond physical symptoms and therefore has a significant impact on the quality of life of patients with endometriosis (Griffith, 2009). The goal of this study is to deepen our understanding of the doctor and patient narratives surrounding endometriosis, to compare these narratives, and to elucidate how they each effect the nature of the doctor-patient relationship in conditions of diagnosed endometriosis and non-diagnosed chronic pelvic pain. If we can identify the differing visions of clinicians and patients, we hope to pinpoint the reasons behind the challenges in the doctor-endometriosis patient interaction. This information could lead to the identification of tools clinicians could use to increase patient satisfaction. This could help decrease potential delay in seeking care in instances of increased pain, improve access to care, and enhance clinical outcomes.

Why have I been invited?
You have been invited to take part in this research because you are either a patient, GP, chronic pain consultant, specialist gynaecologist or obstetrician-gynaecologist who can share his or her experience of endometriosis.

Do I have to take part?
It is up to you to decide. I will describe the study and go through this information sheet, which we will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

As a chronic pain consultant enrolled in this study, you will participate in an interview regarding past experiences with endometriosis patients or patients who have presented with chronic pelvic pain. With your permission, this session will be audio-recorded.

Expenses and payments

As a student, I am unable to offer you any money for your participation in this study. However, I do very much appreciate your time and effort.

What are the possible disadvantages and risks of taking part?

It is possible that discussing your experience with endometriosis may make you upset.

What are the possible benefits of taking part?

The study is expected to provide important information on doctors' and patients' narratives on endometriosis. This information could lead to the identification of tools clinicians could use to increase patient satisfaction. This could help decrease potential delay in seeking care in instances of increased pain, improve access to care, and enhance clinical outcomes.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (**07503556455**).

Will my taking part in the study be kept confidential?

Yes, your anonymity will be maintained throughout with you being only referred to by a designated number and the audio-recording only listened to by the researcher. The recordings will be kept in a locked box and the computer used for producing transcripts and for replaying the recordings will be password protected and any information encrypted. Any print-outs will be kept in a locked box and shredded when no longer needed. Recordings and print-outs will be destroyed after the researcher has been awarded her PhD.

What will happen to the results of the research study?

The results of this research study will form a PhD thesis. In addition, the results may be used for publication in academic journals. All results will be kept confidential within the thesis and in any publications. The results will be made accessible to participants through the Durham University website.

Who is organising and funding the research?
This study is part of a PhD project in the Department of Anthropology, Durham University.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Proportionate Review Sub-Committee of the NRES Committee East of England-Norfolk. In addition, this study has been reviewed by the Ethics Committee in the Department of Anthropology, Durham University.

Further information and contact details
Thank you very much for participating in this study. You will be given a copy of this information sheet and a signed consent form to keep for your records. Please let me know if you have any questions or comments. I'd be more than happy to discuss them with you. Please feel free to contact me at the address or email provided below.

Sincerely,

Dr. Véronique Griffith, MD
PhD Candidate, Department of Anthropology
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Conclusion
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